Minutes of a Meeting of the National UK NHS Cleft Development Group

Venue: Microsoft Teams conference call

Date & Time: Friday 12 May 2023 – 9:00 to 13:00

Present	Simon van Eeden (SvE) Chair	Cleft Development Group Chair
	Victoria Beale (VB)	Clinical Director, North West, IoM & North Wales Cleft Network
	Lorraine Britton (LB)	Representing the Trent Regional Cleft Network
	Alistair Cobb (AC)	Clinical Director, South West Cleft Service
	Peri Codling (PC)	Clinical Lead, Cleft Net East
	Rebecca Crawford (RC)	Clinical Psychology CEN Lead
	Claire Cunniffe (CCu)	CLAPA Chief Executive
	Sinead Davis (SD)	ENT & Audiology CEN Chair
	Helen Extence (HE)	Clinical Director, The Welsh Cleft Lip and Palate Unit
	Louisa Ferguson (LF)	Chair of the Cleft Training Interface Group
	Toby Gillgrass (TG)	Lead Clinician, Scotland
	Norman Hay (NH)	Clinical Director, North Thames Cleft Service
	Peter Hodgkinson (PH)	Clinical Lead, Newcastle Site, Northern & Yorkshire Cleft Service
	Khurram Khan (KK)	Clinical Director, West Midlands Cleft Service
	Sarah Kilcoyne (SK)	Chair, NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies
	Kate Le Marechal (KLM)	Clinical Director, Evelina London Cleft Service
	Joanna May (JM)	Paediatric Dentistry CEN Chair
	Ginette Phippen (GP)	Representing the SLT CEN and Lead Groups
	Sandip Popat (SP)	Restorative CEN Chair
	Helen Robson (HR)	Representing Nursing, Nurse in North Thames Cleft Centre
	Craig Russell (CR)	CRANE Clinical Project Lead
	Heather Sahunta (HS)	Cleft Nursing CEN Chair
	David Sainsbury (DS)	Representative for The British Association of Plastic, Reconstructive and Aesthetic Surgeons
	Julia Scott (JS)	Orthodontic CEN Lead
	Marc Swan(MS)	Clinical Director, The Spire Cleft Service
	Guy Thorburn(GT)	Representing the Surgical CEN
	Yvonne Wren (YW)	Chief Investigator, Cleft Collective
	Antonia Yiakumetti (AY)	Patient Engagement Group Representative
In Attendance	Malgorzata Brzoska (from 9:00 to 10:30)	Research Coordinator, Clinical Effectiveness Unit, Royal College of Surgeons of England
Apologies	Christine Couhig (CC)	Lead Clinical Nurse Specialist, Newcastle
	David Drake	Lead Clinician for Cleft Care Scotland
	Chris Hill	Clinical Director, Northern Ireland Cleft Service
	David Landes	Public Health Consultant
	Jason Neil-Dwyer (JND)	Clinical Lead/Director, Trent Regional Cleft Network
	David Orr	Plastic surgeon and cleft surgeon, Dublin Cleft Centre
	Siobhan Sawey	Paediatric audiologist. Northern Ireland Cleft service
	Alistair Smyth	Clinical Lead, Leeds Site, Northern and Yorkshire Cleft Service

<table>
<tr><th colspan="2">Item</th><th>Notes</th></tr>
<tr><td>1.</td><td>Apologies, absence and welcome to new members and invitees</td><td>The chair (SvE) welcomed the Cleft Development Group (CDG) to the meeting. The group joined the meeting via Microsoft Teams teleconference. Apologies were given for those unable to attend (see above). All attendees introduced themselves.</td></tr>
<tr><td>2.</td><td>Minutes of the Cleft Development Group meeting, 11 November 2022</td><td>The minutes of the CDG meeting on 10 November 2022 were reviewed and approved as a true and accurate record of the meeting.</td></tr>
<tr><td>3.</td><td>Matters arising</td><td>
<table>
<tr><th>Actions from Cleft Development Group meeting: 10th November 2022</th><th>Owner</th><th>Due Date</th></tr>
<tr><td><u>Action 10/11/22:5.1:</u> SvE to replace Martin Evans with Imogen Underwood for future circulation of/request for CD reports to the CDG.</td><td>SvE</td><td>23 May 2023</td></tr>
<tr><td><u>Action 10/11/22:5.2:</u> Surgical CEN to discuss how to manage non-cleft referrals and report back to CDG.</td><td>Surgical CEN Chair</td><td>23 May 2023</td></tr>
<tr><td><u>Action 10/11/22:5.3:</u> SvE to consider how to respond to the questions and discussion around how best to support Bristol.</td><td>SvE</td><td>TBC</td></tr>
<tr><td><u>Action 10/11/22:6.1:</u> CDs to promote the ENT & Audiology CEN to relevant colleagues and suggest booking the CEN meetings into study leave.</td><td>CDs</td><td>December 2022</td></tr>
<tr><td><u>Action 10/11/22:7.1:</u> CR to provide information to CDG members as to the kind of points it would be useful to include in their letters of support.</td><td>CR</td><td>December 2022</td></tr>
<tr><td><u>Action 10/11/22:7.2:</u> CDG members to draft letters of support and send to CRANE for collation and submission.</td><td>All</td><td>CR to advise</td></tr>
<tr><td><u>Action 10/11/22:7.3:</u> Audiology/ENT CEN to advise CR if they know of anyone who would want to liaise with CRANE on analysis of the NHSP data linkage.</td><td>Audiology/ ENT CEN Chair</td><td>CR to advise</td></tr>
<tr><td><u>Action 10/11/22:7.4:</u> CDG members to return comments on CRANE 2022 Annual Report by 25 November.</td><td>All</td><td>25 November 2022</td></tr>
<tr><td><u>Action 10/11/22:7.5:</u> CDG members to note date of CRANE events and email crane@rcseng.ac.uk to register.</td><td>All</td><td>30 January 2023</td></tr>
<tr><td><u>Action 10/11/22:7.6:</u> CR to circulate full presentation to all CDG members following the meeting.</td><td>CR</td><td>Immediate (completed14 November 2022)</td></tr>
<tr><td><u>Action 10/11/22:7.7:</u> CDG members to contact CR if they would like assistance with interpreting the funnel plots in the presentation.</td><td>CR</td><td>December 2022</td></tr>
<tr><td><u>Action 10/11/22:7.8:</u> CR and SvE to agree wording for CRANE website about the timing and nature of the outlier process and the informal approach being used in the interim.</td><td>CR/SvE</td><td>December 2022</td></tr>
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Action 10/11/22:7.9: CR to arrange external review of the CRANE outlier process.	CR	TBC
Action 10/11/22:13.1: CDG members to advise LF if they are able to host a trainee asap.	All	1 December 2022
Action 10/11/22:13.2: SvE to add discussion about how to ensure TIG remains the gold standard for UK cleft training to the agenda for the next CDG meeting.	SvE	23 May 2023
Action 10/11/22:14.1: SvE to add a discussion about the government's information for parents about cleft lip/palate to the agenda of the next CDG meeting.	SvE	23 May 2023
Action 10/11/22:14.2: CDG members to share any data/information they are aware of in relation to non-accidental injury/death in children with cleft.	All	TBC

Action 10/11/22:5.2: SvE informed that he has not received the report from Guy Thorburn from Surgical CEN discussion on management of non-cleft referrals. The discussion with GT was on the funding of these services and how to integrate them into their pathways, and how much of a burden of care they are on cleft teams. SvE asked the members if they had anything to add.
GP said that she had been looking at the access to speech therapy, and non-cleft velopharyngeal incompetence was one of the criteria, but the information was not specific. In the past, it had been difficult to find funding and resources for those patients. GT added that these patients tend to be resource intense.
SvE proposed this could be "another thing to pick up within the specification", and that (people) come for the expertise of the group with regards to those patients. PH noticed that now there is an opportunity to get this funded, as ICBs are looking for the group's expertise and there will be discussions. AC felt that referrals pertaining to oral and nasal sphincters were increasing and that perhaps cleft lip and palate teams could follow the craniofacial commissioning model which is more open-ended rather than being specific to cleft lip and palate and non-cleft speech sound disorders but that funding should accompany this.
SvE said the new way of commissioning might create an opportunity for raising that with local commissioners and getting the pathways funded.
Action 10/11/22:5.3: SvE asked AC if he would like to brief the meeting on the discussion and action on how to best support Bristol. AC said he would be happy to pick it up in the regional slot.
Action 10/11/22:6.1: SD said the CDs to promote the ENT & Audiology CEN had a great response. There were several new members at the last meeting. Missing Northern Ireland (?). There Is no-one from the Isle of Man, North Wales, Liverpool and Manchester. The contact person said they were not interested. SD is going to follow it up further.
Action 10/11/22:7.1: CR thanked for providing letters of support for CRANE. They helped uplift the funding on a one-year basis. (There has been an e-mail confirmation for that).
Action 10/11/22:7.3: SD updated CR on Audiology/ENT CEN in that there is someone interested in the post (analysis of the NHSP data linkage). The current secretary (Victoria Parfitt) will liaise with CR at least on a temporary basis unless someone else is appointed. SD assured CR she would contact him after the meeting.
Action 10/11/22:7.4: CR: CDG members returned comments on CRANE 2022 Annual Report, and it has been in the public domain since early December.

	Action 10/11/22:7.6: Full presentation following the meeting has been circulated to all CDG members, as well as dates of CRANE events. To register, please email CRANE (CRANE@rcseng.ac.uk). **Action 10/11/22:7.7:** CR re-iterated that If CDG members would like assistance with interpreting the funnel plots in the presentation, or would like to discuss it, to please contact him. **Action 10/11/22:7.8:** SvE and CR had agreed wording for CRANE website about the timing and nature of the outlier process and the informal approach being used. It has been published on the website. **Action 10/11/22:7.9:** CR provided an update on his discussion with the academics at the CEU (primarily Jan van der Meulen) about arranging external review of the CRANE outlier process. He reported that this is not something that would be done for any of the other National audits that they host, and that publishing the risk adjustment process in peer reviewed journals is sufficient. CR offered rediscussing the matter If CDG members feel this is insufficient. SvE shared his opinion that it sounded reasonable. No-one else responded. CR shared the desired risk adjustment process to follow for annual reporting in the public domain: publishing the identification of determinants, publishing the model, and after that having been accepted for publication, it would be presented to CDG for consent to use in the outlier policy. **Action 10/11/22:13.1** LF informed the group that she had received some advice from CDG members on hosting a trainee. She said it is enough for this year, and there will be the same request for next year. **Action 10/11/22:13.2:** How to ensure TIG remains the gold standard for UK cleft training to be added to the agenda for the next CDG meeting – SvE and LF agreed to discuss it in detail under the training agenda. **Action 10/11/22:14.1:** GP shared her opinion on the government's information for parents about cleft lip/palate. It looked clear and accessible. It is a written information available on the gov.uk website. She thought it would be useful to have some feedback from CC and CLAPA. CC agreed. GP shared an idea to take it to PEG. SvE offered to find out who the authors were once GP and CC have got back to him with their feedback. CR was concerned that the written information on the website is not accessible for the significant proportion of the population, as 20% of all the population are illiterate, 10% have dyslexia, and many others are not native English speakers. He shared an example of Scotland that has been working on augmented reality interactive information on various operations. The BBC filmed that with a family and the benefit it has for literate and illiterate families. The report was supposed to be released in late May (1 week after the CDG meeting). The pilot is being trialled in a formal manner academically, but so far it has been very well received. Scotland is going to work on some YouTube information sheets. It would be worth talking about and work on as a community to ensure the view on it is not dominated by one service. CR is planning to bring the outcomes of the trials to the conference next year. SvE shared his opinion that it is brilliant and would be useful. SvE said the information about the project will be included to the feedback to the NHS. **Action 10/11/22:14.2:** SvE asked if there was any information to share on the issue on non-accidental injury/death in children with cleft. No-one responded. **Action 10/11/22:14.3:** Include information to feedback to the NHS about the Scottish project of providing a non-written information about cleft on YouTube in a response to those that are illiterate, have dyslexia or are not native English speakers.
3.b Presentation given by Anthony Prudhoe About the changes to the structure and	SvE welcomed Anthony Prudhoe, the NHS Senior National Programme of Care Manager to the meeting and thanked him for agreeing to meet with the CDG at such short notice. SvE provided the background for the invitation namely to discuss Integrated Health Boards. SvE had watched the recording of the NHS

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commissioning within the NHS	England Board Meeting in February 2023, when integrated care boards were approved. At the meeting the Head of Specialist Commissioning said that there had been extensive clinical collaboration and consultation, but none of the CDs had been contacted or aware of the programme. SvE himself had been informed about it by Jason Neil-Dwyer, Trent CD at Nottingham University Hospital and received a document from PH (and shared with the CDG) who had also come across it by accident. SvE asked AP to share his opinion about NHS Integrated Care Boards, and to provide some background and a summary of the project development. AP pointed out that he is a stakeholder and is not in charge of the project. AP shared his personal excitement from an integrated services perspective. The project has been led by NHS England's future commissioning model programme oversight group and trialled for years, in terms of what services should be delegated or nationally commissioned. Several organisations have been involved in the project's design and development, and stakeholder testing took place. The information is available on the NHS England website. The Clinical Reference Groups provided the list of the services suitable for local commissioning. Cleft is one of them. The list had been sent to SvE prior to the CDG meeting. Video recordings and reports from board meetings are available on the NHS England website. AP explained that NHS England is going for Integrated Care Boards and care systems to improve access to local services and ensure equality of service delivery across the country. There has been a step together approach to consolidate the decision making between NHS England and ICBs for specialised services. All ICBs will establish formal joint working arrangements with NHS England via nine statutory joint committees from June 2023 to June 2024 with a view to moving to delegated commissioning arrangements from next year. The committees will be divided geographically and will consider locally provided services. Integration will bring partnership of NHS, local authorities, and health systems (including social care). It will benefit hospitals by improving outcomes and reducing inequalities. AP reminded CDG that the process is still in progress. He advised the meeting to regularly check the updates and documents on NHS England websites. SvE appreciates the idea of joint working within NHS Specialised Commissioning and the ICBs before moving fully to ICBs. PH was glad that the deal has not been done yet, as the document was enacted on 1 April 2023, and he saw it in the second week of April 2023. He noticed that the document mentioned involvement of experts in the ICB, but no-one in his trust has been involved even though they offer many specialist services. PH shared his concern that there is comparably less involvement with the Commissioners, and it will bring less benefits to both sides than in other projects he has had experience with. Overall, PH found the project positive and would like to be involved. PH shared his opinion it is better for CDG representatives to join the project quickly, as that is usually more beneficial for their services. AP added this will bring fundamental changes. The setting of standards for the cleft lip and palate service delivery will still be nationally and clinically led, but it will put hospitals, commissioners and community-based services into an integrated system. GP can see opportunities from the project, especially in speech and language therapy and services for children. She was concerned that inequities across the country would remain, as negotiations would still be local, and the budgets should be population-based. PH asked what the specific benefits from the project are, and what the "integration" means, as it was not clearly expressed in the document.

	AP agreed with GP on the need of pushing towards population-based budgets. The need to commission cleft and speech and language therapy as part of packages is a step in the right direction. AP agreed with PH that hospitals and the services within them should have a voice in the process. AP believes that the change will integrate surgical services, speech and language therapy and community services. AY was concerned that there will be inequities and differences in access to treatment and the treatment itself. Social media will highlight the differences even further, as patients discuss and compare their treatments. AY asked whether patients will be confined to their local cleft team, or they will be able to obtain a second opinion from another cleft team. AP answered that patients will have opportunity to obtain the second opinion and access treatment from another cleft team. The project will consider patient and public voice perspective. When the process is started, local systems will be informed about it. KK asked if during the first year and going forward the funds will stay the same, will be decreased or increased. AP answered that at this stage focus should not be on funding. The plan is to develop a population-based funding model. CC shared her experience with adult patients who seek the second opinion or prefer a cleft team outside of their area, and the process for them is difficult. CC asked what the specific process will be for obtaining patients and their parents' opinion. AP did not know the process as that would be managed locally. The expectation is that stakeholders, patient groups are involved. CC: CLAPA supports people across the UK. How can they access information to support people affected with cleft when the service is managed locally? AP did not know the answer but promised to talk to Harry Lewis and contact CC after the meeting. AY shared her perspective that the services seem to be centralised, and the ICB project takes them 20 years back, when they were local. AP pointed out that the services have never been centralised. There seems to be a disconnect between the proposal, the current actions, and the involvement of patient and public voice. AP is going to speak to the engagement team and NHS England and update CC and AY. AP answered to PH that chief executives are a part of the project. He advised to make sure that hospital senior people stay updated on shared information and refer to the board on the situation in their local hospital to be a part of the programme. NH agreed with AY opinion that centralisation of services was a good thing. The system was not perfect, but support from other areas was available for patients, and NH worries that this will be lost. NH said that the NHS England had many opportunities to talk to specialists across the country about the project and their engagement. The project should have included the plan of implementation and the list of desired outcomes. NH asked how services will be funded if there is a patient from a different area. AP admitted that there might have been a communication problem, but he said that nevertheless, a lot of information has been available to access. He pointed out that the discussion should not focus on how the project will change specific services, but on the opportunity of integration and the delivery of services, that is currently missing. AP believes there is a chance to improve the existing state, full of inequities, where patients do not have access to the services because they are not integrated. NH said this is encouraging and he will take it back to the right team.

	PH said that his chief executive as a champion of engaging diversity in the community, she would be supportive, and it would be great to talk to her. MS shared his opinion that the message from NHS England was unclear, including "integrating with community services". He asked how the project is going to address the financial issue of community services? MS felt that uploading documents to the website is an inefficient way of communication, as busy clinicians will most likely miss it. Instead he felt that NHS England could have called SvE, and he would have passed the information to CDG. MS is pessimistic about the project. GP said that the points on social care, partnership and commissioning are not specific in the document. How will this project affect central teams? AP answered that it is important to integrate commissioning to bring the services together. AY said she can see potential benefit in terms of relieving pressure on the central teams but she was concerned that specialist knowledge would be diluted. She pointed out that some patients tried to consult their local dentists, but they did not have knowledge about cleft care: therapists might not be trained or have the knowledge on cleft. AP answered that the situation described by AY is taking place right now. Groups of specialists, such as CDG, have a leadership role and should encourage knowledge and training. PH said that CDG members should take initiative and contact their local committees and ICBs and offer their help and expertise, to work on improving services. SvE noticed that the geographic footprint of cleft services does not match the ICBs. Some clefts services will have to meet with six or seven different ICBs. He asked how NHS England is going to make sure that there is equal service delivery and access to services and funding across the country? AP answered that funding is going to be population based. There is no natural fit for ICBs because the services existed first. It will work if people collaborate. AP decided to open a formal communication channel to CDG through SvE, and to update the CDG formally on new information. CR said there are two processes in place to ensure equity in England and Wales: The dashboard, and CRANE. The process measures outcome and enables demonstration of the areas of service where equities and inequities exist. CRANE and London School of Hygiene & Tropical Medicine just submitted a paper for that, and it is going to be published shortly. AP promised he would get back in touch with CR about it. SvE thanked AP for joining the meeting. He appreciated that communication has been established. It is important that everyone work together on this, and that cleft is a part of the conversation. SvE had asked the chair of CRG meetings for minutes from their meetings in the future The chair is willing to come to CDG meetings as necessary. **Action 12/05/23:3.1:** AP will talk to Harry Lewis after the meeting and provide CC with information on how people affected with cleft across the UK can access information and be supported by nationwide organisations when cleft services are managed locally? **Action 12/05/23:3.2:** There seems to be a disconnect between the proposal, the current actions, and the involvement of patient and public voice. AP is going to speak to the engagement team and NHS England about the signalled impression of disconnect between the proposal, the current actions and the involvement of patient and public voice, and update CC and AY.

4. CDG Patient Engagement Group (PEG)	SvE: Asked GP to give patient engagement group update. GP: Attended the last meeting on 27/3/2023 where a small group was in attendance. AY fed back about the November CDG meeting and the group responded positively to the amount of time given to the patient engagement group by the CDG. The PEG are aware of the fact that not all teams filled in the original spreadsheet of questions and have decided therefore to focus on fewer issues and to also approach the individual CEN groups about certain issues. The PEG have decided to focus on access to dentistry in the community, adult self-referral to cleft centres, biographical details of team members on centre websites and choice of treatment centres. One of the main outcomes of the last PEG meeting was to push for an agreement about adult self-referral. Although there is recognition that, and it was well minuted, that there are different approaches by different teams and that the service specification says specifically that referrals will be managed locally and responded to as decided by the local team, there is still some frustration about not being able to get their GP to get them back into the system. The PEG felt that it would help if it was possible to contact a cleft centre directly even if there was a subsequent need for a triage or a psychology reintroduction into the service, or whatever their locally determined pathway is. The PEG meeting ended with a discussion about having an adult focus group and a parent's focus group within the PEG to be able hone in on the issues particular to those groups. SvE thanked the CDs that did respond to the PEG questionnaire and confirmed that there were a number of CDs that hadn't responded. SvE agreed that it would make it easier if there was general consensus on an adult referral pathway and he asked the CDs to think about whether it is possible to make access for adult patients to cleft services the same across the country? JM asked if the concerns were about dental access in general or about access to dentists that are happy to treat children or adults with a cleft? GP: Speaking on behalf of the group replied that it's both. JM: Informed CDG that the paediatric dental CEN are currently doing a questionnaire looking at access to dental care for children with cleft because it is known that it's a problem across the country; they are also hoping to do additional webinars and training for dentists and for undergraduate students about cleft lip and palate. So hopefully that will increase knowledge. GP: I think it would be great for the group to know about all that work that's going on and she felt that the direct links with the CEN groups make a lot of sense. SvE: asked JM to involve SP to get a joined up view of both paediatric and restorative dentistry and SP agreed that it would be good to work together to target undergraduates. CC: Highlighted a case of an adult patient who had difficulty accessing care from a cleft team out of their region. AY Re-iterated the difficulties accessing cleft teams and re-iterated the plea for access via self-referral and suggested a link or form on the CLAPA website that might make this process easier. PH felt that self-referral is difficult especially if the referral is about appearance. He suggested that CDs agreed to accept all GP referrals regardless of the area so that the patient being referred could be seen by the whole adult cleft MDT. A long discussion followed about access for adults to cleft care with contribution from KLM highlighting difficulties with a high volume of adult patients from

	within and without their region meaning long waiting lists; from AY about her personal journey and accessing private care; and from CR about the Scottish model and, access for all and the need for waiting lists and the other priorities in the NHS following Covid. SvE asked the CDs, that if we're unable to get a universal policy for the referral process, to have a look at the patient engagement questionnaire and to give a breakdown of the structure of their adult services so that patients can know how to access services in each area of the country and perhaps these could then be shared with CC so that CLAPA is able signpost patients more accurately. CC agreed.
5. Cleft Specification	SvE: The aspiration that CDG has to relook at the cleft specification is very timely as NHS England under the auspices of the ICBs and the CRG are going to ask for revision in the next year or 2 meaning that CDG has pre-empted this. SvE thanked the groups have already got back to him with their proposed changes and he encouraged those groups that had not, to look at the cleft specification and to get back to him with any proposed changes. SvE suggested looking at this in more detail at the next meeting.
6. Feedback from Cleft Centres (UK)	PH spoke to the written update from the Newcastle Site, Northern & Yorkshire Cleft Service. AC spoke to the written update from the South West Cleft Service. SvE asked AC to expand on the plan for mutual aid and on the harm review. AC explained that it was difficult to find access to mutual aid from other centres due to pressures of their own; the plan that had been formulated by managers to get cleft surgeons to operate on weekends in Bristol had not been discussed with the Bristol cleft surgeons and had not taken adequate account of theatre assistance and the post-operative care pathway and as such had not gone ahead. AC also explained that changing the borders for the South West cleft service had been explored but that this was not viable. AC explained that from the harm review perspective Bristol children's hospital is too small a hospital on a footprint that is too small to be able to increase capacity enough to deal with the backlog; furthermore there are staffing issues made worse by congestion charging etc and he will go through the South West regional Commissioners again to try to come up with a solution.. HE spoke to the written update from the Welsh Cleft Lip and Palate Unit. KK spoke to the written update from the West Midlands Cleft Service. MS spoke to the written update from the Spire Cleft Service. LB spoke to the written update from the East Midlands and Nottingham Cleft Service. PC spoke to the written update from Cambridge Cleft Service. NH spoke to the written update from the North Thames Cleft Service. KLM spoke to the written update from the Evelina London Cleft Service. VB spoke to the written update from the North West, IoM & North Wales Cleft Network. CR spoke to the written update from the Cleft Surgical Service for Scotland. **See Appendices 1 to 14**

7.	**Feedback from CENs**	SVE: Apologised for the fact that time was running out and he asked the CEN leads if they would be happy for their CEN reports to be appended to the meeting minutes and distributed to CDG after the meeting-there was agreement from the CEN leads for this to occur.
8.	**Feedback from CRANE**	CR provided an update on CRANE. CR sent the copy of his slides to CDG and he suggested that given that the presentation is very similar to the report given to the Craniofacial Society conference, he would rather focus on 1 particular slide and use that to direct the discussion. SvE: Agreed and felt it was great use of time. CR shared the slide: CR asked for feedback on the content of next year's preliminary report and a slight change to the reporting timeline and discussion about a CRANE steering group. CR outlined that the preliminary report from CRANE was shared with CDs in May and not only dealt with consent and data completeness, it also gave an indication of potential outlier status by reporting on all the outcomes as well. CR reported that this is very time consuming as the reports are due around Easter time and with current staff shortages he feels the workload is such that CRANE won't be able to provide information on outlier status and information on outcomes in the future. He asked CDG if CRANE could rather concentrate on consent levels and data completeness in the preliminary report to let CDs know about gaps in their data? He explained that at the time of the preliminary report it is not possible to change outcomes so reporting of these later in the year with activation of the outlier process makes more sense, but changes can be made to the quality of the data completeness. CRANE would like to focus on driving data completeness and CRANE will endeavour to provide this data at the beginning of March rather than beginning of April. There are not going to be any changes made for the extract for the final report, the outlier policy, and the publication of the final report in December. SvE thanked CR and asked for any comments? GT felt that this was the right approach as incomplete data sets give rise to unreliable data about outcomes; he mentioned that this had been discussed at the surgical CEN and that there was support for this. LB wanted clarification about the timing of the outlier letters and when the centres would get first sight of their outlier status? CR confirmed that in the proposed reporting system the outlier letters that would go out in August (rather than in April) and this would be the first time the centre finds out about their outcomes rather than seeing these in the preliminary report earlier in the year; the final report would follow approximately 3 three months later in December. In summary then CR is proposing reporting on data completeness in March and then in August/early September, once the analysis is done the outlier process is started by writing to CDs to share their outcomes which will include the funnel plots, a spreadsheet of each centre's performance across all domains and outlier status if applicable. CR moved onto discussion about the proposed CDG steering group for CRANE: In view of the new CRANE contract and the governance of other national audits CRANE feels compelled to ask for a separate more detailed steering group that would meet for a maximum of 90 minutes, two or three times a year. CR suggests that the formation of a CDG subgroup is one that is more responsive like the QMIC Group. CR explained that this would be about the governance of CRANE with input from a slightly wider clinical group meaning that it's not just his clinical input that drives CRANE's agenda; he went on to say that the sub-

		group would also need to have lay representation. He asked CDG whether this was something that CDG would be happy to support and facilitate? SvE: felt that CRANE's request was reasonable, and he asked whether there would need to be representation from all the specialities and the CDs? A discussion followed about representation on the group and where the representatives would be drawn from. CR felt a group of 5-6 members would be adequate; LB suggested members from the CEN groups and PH felt that both geographic and speciality representation was important which might mean a bigger group than 5 or 6 but if the meetings were virtual, he felt that this shouldn't make a difference? An agreement was reached that the CEN leads and the CDs would go back to their groups and teams to see if there were any willing volunteers to sit on this group and that this could be finalised at the next meeting . **Action 12/05/23:8.1:** The CEN leads and the CDs will go back to their groups and teams to see if there were any willing volunteers to sit on this group and that this could be finalised at the next meeting .
9.	**Quality Monitoring and Improvement Committee (QMIC)**	SvE gave feedback on the quality monitoring and improvement committee meeting in March 2023: The meeting focussed on variability in outcomes. CR presented on variability of outcomes across the country- he explained that although the funnel plots were starting to narrow slightly, there is still a lot of variability between cleft centres. CRANE is trying to understand why this variability is present and they have started focussing on variability in speech outcomes and dental outcomes with the lead groups to look at this in a bit more detail . This is to be discussed at the next QMIC meeting. **Action 12/05/23:9.1~~7~~:** Reasons of variability of outcomes in speech and dental outcomes across the country will be discussed at the next QMIC meeting
10.	**Feedback from CLAPA**	CC spoke to the written update from CLAPA **Cleft Lip and Palate Association Update** Cleft Development Group meeting 12th May 2023 #SaveCLAPA In our last update we told you about our #SaveCLAPA appeal that we launched in October 2022. Months of dwindling income left us with two choices – make drastic cuts to vital services or raise a huge amount of money fast. The middle of a cost-of-living crisis felt like the worst time to ask, but our community deserved to know how desperate the situation was and how badly we needed help. I'm delighted to tell you that the #SaveCLAPA campaign was very successful and raised over £100k, allowing us to end 22/23 without a financial deficit and more importantly increase the number of people giving to us monthly so we have an increased income we can rely on. However, I wish I could say that was the end of it – that we're safe and secure now and can stop worrying. Sadly, this isn't the case and, as a group that has always been so supportive of CLAPA, we want you to know the truth which is, if we go back to the way things were, it won't be long before we're in that same scary place again.

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As you all know only too well, cleft isn't going anywhere and, as such, there will always be a need for the services CLAPA provides. I don't want the future of these services to ever be in doubt again. I want CLAPA to be something that the cleft community can rely on year after year, generation after generation.

To do this, we need your help. If you are not already making a monthly donation, you can help us that way (www.clapa.com/donate), but you also help by raising awareness not only of CLAPA's service but our charitable status and need for funding. CLAPA receives no government or NHS funding and as a small charity with a tight budget, even one bad month can spell disaster.

As I previously updated we do have a fantastic new Head of Income, Mikaela Conlin-Hulme who, thanks to a generous grant from the VTCT foundation, is in the process of finalising the new Income Generation Strategy.

Cleft Lip and Palate Awareness Week 2023

6th-14th May is Cleft Lip and Palate Awareness Week, and hopefully you've already seen our posts and updates across our social media channels (@clapacommunity on Instagram, Facebook and Twitter). Our aim is to get our myth-busting videos and other posts in front of as many eyes as possible this week, and I'm delighted to say that halfway through the week we've already reached 200,000 people!

The community response has been truly incredible this year, with thousands of patients, parents and carers posting about their own cleft journey to help raise awareness in their networks.
There's still time to get involved – please share CLAPA's posts along with a message about why you're supporting Cleft Lip and Palate Awareness Week this year.

For more information and updates, visit www.CLAPA.com/AW23.

Step up for Cleft Lip & Palate
As part of Awareness Week, we also have a live virtual fundraising challenge event underway – Step Up for Cleft Lip & Palate. This challenge has had a bit of a face lift from previous names and a rebrand from Step up for CLAPA to make it clearer what the cause is and to increase the awareness it can raise!

The challenge this year is for the community as a whole to get involved and do a loop of all the NHS cleft Clinics in the UK! Yes that's 1464 miles! Participants (113 at the time of writing this) can form teams, family groups or even go it alone and can run, walk, hop, skip even salsa the distance! I'm taking part and have 35 miles to cover by the end of the week! Everyone taking part has been sent a pin badge and a list of conversation starters about cleft so they can raise pounds and awareness! So far, we have raised over £8,400!
It's not too late to take part as we are running the challenge up to the 14th May! Full details can be found at www.clapa.com/stepup.

Staffing Changes

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	We are in the process of recruiting for 3 new members of staff – a Data Officer, Fundraiser and Finance Officer. Interviews have been held for all positions and appointments are in the process of being made. For the full staff team, please go to https://www.clapa.com/about-us/meet-the-team/. CLAPA Trustees We have recently advertised for 3 new Trustees – a Clinician, someone with a comms, media or PR background and a charity sector professional. We have had a really good response and shortlisting is currently taking place with a view to interviews being held this month. For the full board of Trustees, please go to https://www.clapa.com/about-us/meet-the-team/board-of-trustees/. CLAPA Link people We now have a CLAPA Link person in place for virtually every Cleft Team – thank you for all your help in achieving this! We are keen to understand if this role is working and if the information that we are sharing is being disseminated within teams. Please contact Ellie Dale, Engagement and Services Manager, at ellie.dale@clapa.com for more information or to nominate someone as the link to your service. CLAPA Finances We are currently in the process of finalising the Annuals Account for the financial year ending 31st March 2023. The financials are reporting an in year surplus (2022: in year deficit) with the reserves above 3 months (our reserves policy is 3-6 months). The Annual Accounts will be audited in June, and once agreed at the AGM, they will be available to share. Claire Cunniffe Chief Executive claire.cunniffe@clapa.com
11. Research	a. Bristol-Cleft Collective b. NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies c. Early Career Researchers Group (ECRG) d. Cleft Multidisciplinary Collaborative e. Early Career Researchers Group f. Clinical Studies Group update g. The Side Lying and Upper airways Maintenance in Babies Requiring Surgery (SLUMBRS) study h. Discussion about Feedback to CDG from Centre for appearance research i. Discussion about possible surgery project **See Appendix C: Research Updates – Appendix 1** **Early Career Researchers Group / Cleft Multi-Disciplinary Collaborative Cleft Development Group Report Nov 2022** **Background** The Early Career Researchers Group (ECRG) and Cleft Multidisciplinary Collaborative (CMC) exist to expand and enhance the opportunities for its

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	members to engage with high quality research and quality improvement projects, benefiting NHS Trusts and ultimately our patients. It is open to all disciplines involved in cleft care, regardless of an individual's clinical or research experience. **Current membership** Sophie Butterworth was appointed as the new Chair of the ECRG following the March hybrid face to face and virtual meeting. Since March we have had two virtual meetings (June and October 2022). The October session included a virtual CPD session on analysis of large datasets using Stata and R presented by Penny Birmpili a clinical fellow at the Royal College of Surgeons of England. We have over 30 members from a range of disciplines, speech and language therapy and surgical specialties have the greatest representation but efforts have been made to encourage more specialist nurses and psychologists to join. This has led to three new members and representatives from the Centre for Appearance research plan to join our next face to face meeting in April. **Previous Projects** 1. Scoping Review of Outcomes for Children with Bilateral Cleft Lip and Palate Current status Data extraction is complete in the different professional groups. There are large amounts of data from speech, surgery and dental. This will be written up over the course of the rest of the year as a broad scoping review identifying gaps in the research with regard to BCLP outcomes. These are likely to be separate publications. 2. Unrepaired Cleft Palate Survey and Audit Current status – complete • Oral presentation at CFSGBI, April 2019 • Poster presentation at EACPA in Utrecht, June 2019 • Published in CPCJ 2021 A survey of cleft units in the UK was conducted. This project aimed to identify the number of children with intentionally unrepaired cleft palates in each unit within the UK. From the literature this has never been investigated. Each cleft team had a handful of children, born with cleft palate, which were intentionally left unrepaired. The decision not to repair the palate in these children was often made in conjunction with many other healthcare professionals and the risks of surgery were weighed up against the perceived benefits. These children had very complex medical needs and spent lots of time in a hospital setting with many different specialists involved. Some of these children had a recognised syndrome such as Cornelia de Lange. All of the patients were found to be non-verbal and were PEG fed. Many of these patients are tricky consultations for clinicians and following the survey it was decided to continue this piece of work as a qualitative survey evaluation involving the specialist nurses and psychologists. This is to try and find out a little bit more about these patients to support some of the families that have found it difficult to accept that leaving the cleft palate unrepaired may be better for their child, particularly where the anaesthetic risk is high.

	A second expansion of this study was to conduct a quadcentre audit, looking at the timing of primary lip and palate repair, any patients that had a delayed repair and the reasons for this and also pull out the actual numbers of deaths and intentionally unrepaired cleft palate patients. This was a retrospective audit involving 1826 patients over 5 NHS cleft sites. It was presented in November 2019 at the NorCleft meeting in Manchester and was published in 2021. 3. Non-Interventional Factors Influencing Outcomes in Velopharyngeal Function in Initial Cleft Palate Repair - A Systematic Review Current status • Protocol published (Systematic Reviews 2019 8:261) • Funding received from CFSGBI to fund 8 licenses for Distiller SR (systematic review software) for 12 months. • Three levels of screening completed and data extraction of 383 papers completed. • Data analysis completed • Manuscript soon to be submitted • Poster presentation at CFSGBI 2021 • Presented at International Cleft Meeting 2022 Background This systematic review aims to inform the development of a screening tool which preoperatively predicts which children are likely to develop velopharyngeal insufficiency, one of the causes of poor speech outcomes, following cleft palate repair. This would be highly beneficial as it would inform pre-operative counselling of parents, allow targeted speech and language therapy and enable meaningful comparison of outcomes between surgeons, techniques and institutions. Currently it is unclear which factors influence speech outcomes. A systematic review investigating the non-interventional factors which potentially influence speech outcomes following cleft palate repair is warranted. This may be inherently illuminating or provide foundations for future studies. Methods A systematic review will be carried out according to Cochrane methodology and reported according to PRISMA guidelines. Systematic review software will be used to facilitate threestage screening by two independent reviews experienced in cleft lip and palate. Thereafter, data extraction and GRADE assessment will be performed in duplicate by five independent reviewers experienced in cleft lip and palate. Studies reporting the proportion of patients recommended for or who underwent secondary speech surgery for velopharyngeal insufficiency following primary surgery for cleft palate will be included. Study findings will be tabulated and summarised. The primary outcome measure will be further speech surgery (either recommended or performed). The secondary outcome measure will be perceptual speech assessment for the presence of velopharyngeal insufficiency. A meta-analysis is planned. However, if this is not possible, due to the anticipated marked heterogeneity of study characteristics, pre-operative assessment and the recorded outcome measures, a narrative synthesis will be undertaken.

	This systematic review may provide sufficient data to inform the development of a screening tool to predict the risk of velopharyngeal insufficiency prior to cleft palate repair. However, it is anticipated that these findings will provide the foundation for future studies in this area. 4. Outcomes for Robin Sequence Current status • Presented at ECPCA, Utrecht, June 2019 • 10 centres involved in UK • Data on 250 patients • Presented at International Cleft Meeting 2022 • Manuscript in progress We are looking to describe a group of PRS patients born between 1st January 2005- 31st December 2009. We would like to capture basic demographics, treatment details (for example, airway management, feeding methods, age of cleft repair, requirement for revisional surgery), and then record speech outcomes at 18 months (18-24 months), 3 years, 5 years and 10 years (where available). 5 year speech outcomes has been chosen as the primary outcome measure. Data from patients across ten sites in the UK has been collected and analysed. This was presented at ECPCA, Utrecht last June. The sites that were included in this initial project were Newcastle, Liverpool, Northern Ireland, Oxford and Salisbury. Five more UK sites have contribute to this dataset. The definition as laid out by the international consensus – micrognathia, glossoptosis, airway difficulties (+ cleft palate in our case). RS subtype with cleft palate have poorer speech outcomes at 5 years compared to children with cleft palate only but there was no difference by age 10. 5. Impact of the COVID Pandemic on Cleft Surgery Current status • Study has been peer reviewed and is supported by the NIHR Cleft and Craniofacial Conditions Clinical Studies Group • Funding granted from the Edinburgh Clinical Trials Unit for managing the RedCAP database • Endorsed by the Royal College of Surgeons of England • Data collection to date: o 8 units entering data o 651 operations details entered o Data entry closed on 7 June 2021 • Oral presentation at CFSGBI 2021 and ACPA 2022 • Presented at International Cleft Meeting 2022 • Manuscript in progress This study aims to determine the impact of COVID on cleft surgery. This the first time in the UK that a large cohort of patients will be undergoing cleft surgery with such large delays in timing of surgery. Additionally, we do not know how the prevalence of COVID in the community and possibly in patients will affect the postoperative course of children undergoing surgery, particularly in the case of babies and procedures that may bring about a temporary reduction in airway

	volume. Given the relative rarity of COVID in babies and children, it is particularly important that we share data across the UK following the resumption of cleft surgery. This will enable better understanding of perioperative safety and outcomes. Additionally it will provide data to guide practice, in particular the need to suspend/delay elective surgery during further waves of this pandemic. This is also an opportunity to study the impact of delays to planned cleft surgery, in a large cohort and identify any impact on outcomes that may be related to such delays. This study will also examine cleft surgeons experiences of wearing PPE with loupes, headlights or the operating microscope and will study solutions that may prove useful in similar situations. PPE is particularly relevant for cleft surgery, because the surgeons face is close to the patients mouth and the endotracheal tube (ET) for a considerable duration. Cleft surgery requires a Rae tube, curved to lie flat on a patient's chin. Not all units in the UK had access to cuffed Rae tubes in small sizes and this practice has been changing. Our study will report on these changes. Primary Objective • To determine the impact of the COVID pandemic, on elective cleft surgery timings and outcomes. Secondary Objectives • Study individual units screening processes, screening outcomes and their impact on clinical decision making regarding timing of surgery • To determine prevalence of COVID positive tests in infants (and parents where testing is done as part of unit protocols) • Incidence of post-operative complications • Impact on patient follow up (remote or in person) • Duration to return to usual protocol timelines • Surgeons' reports of challenges of wearing PPE and operating with loupes/headlight/microscope Primary Endpoint • Point at which patients are able to have surgery in keeping with UK standards and unit protocols, in terms of timing of surgery. Study Design Study type: Observational Setting: Tertiary cleft centres. All 11 cleft units (16 cleft surgical sites) in the UK will be approached for participation. This will include cleft surgery consultants and trainees. There is an well-established network and history of multicentre collaborative studies across the 11 UK cleft centres. Study Duration: Until UK Cleft surgery has caught up with the COVID backlog. Follow up duration: 3-4 months, until patients have had at least one post-op review 6. Delphi Fistula Project Current Status • Rounds 1 and 2 of Delphi Survey completed • 35 members for expert panel

	o 14 cleft consultants o 6 SLTs o 6 Cleft specialist nurses o 3 Paediatric Dentists o 6 Orthodontists • Accepted for presentation at ICCPCA 2022 • Manuscript in progress The aim of this study is to provide a consensus opinion on how Cleft Teams in the UK report fistulae. An expert panel was invited to complete a short series of surveys, with results anonymised, to demonstrate an unbiased consensus opinion. The questions will not primarily be designed to give all answers to the many questions fistulae pose, but more to provide as close to a robust minimum data set as can be achieved. 7. Assessing Learning Curve in Palatal Surgery using a Sommerlad Radical Intravelar Veloplasty Current Status • This proposal is being redesigned and incorporated into a larger NIHR doctoral fellowship application being submitted by Sophie Butterworth • To be submitted for peer review by the NIHR Cleft and Craniofacial Conditions Clinical Studies Group when complete Aims • To identify if a learning curve can be observed among surgeons performing a Sommerlad style palate repair • Does the training pathway affect the learning curve? Methods TBC New Project ideas 1. Mahaveer Sangha – New surgical member Interested in completing a study looking at socioeconomic factors in relation to patient outcomes. Discussed ideas within the group and felt using the Cleft Collective data would be beneficial. Alex Gormley agreed to kindly 'Buddy' with Mahaveer to introduce him to the team and help him to start forming a research proposal. 2. Using social media for PPI Following on from our PPI CPD session in March on 'Seldom heard voices' we discussed the possibility of using social media to discuss research questions relevant to the group. The purpose of this was two-fold, firstly to reach people in the community who may not volunteer to participate in focus groups or research panels ordinarily either due to practical issues (childcare, financial, work arrangements) or other concerns (difficulty with speech and being understood). Secondly, to provide data that could be submitted as part of research proposals before people have been awarded funding for PPI.

We plan to take this idea forward in our next face to face session and will look for some relevant studies such as work by Sam Burr (Bristol) in the meantime.

Completed Projects / Publications

1. The Cleft Multi-Disciplinary Team Collaborative: Establishing a multidisciplinary network to support cleft lip and palate research in the United Kingdom. Sainsbury DCG, Davies A, Wren Y, Southby L, Chadha A, Slator R, Stock NM; Cleft Multidisciplinary Collaborative. Cleft Palate Craniofac J 2019;56(4):502-507.

2. Non-Interventional Factors Influencing Velopharyngeal Function For Speech In Initial Cleft Palate Repair: A Systematic Review Protocol.
Sainsbury D, Williams C, Blacam C, Mullen J, Chadha A, Wren Y, Hodgkinson P.
Systematic Reviews 2019 8:261

3. A Closer Look at the Reasons for Delayed Primary Cleft Surgery and Unrepaired Cleft Lip and /or Palate in Five UK Cleft Centres.
Sophie Butterworth, Clare Rivers, Marnie Fullarton, Colm Murphy, Victoria Beale, Jason NeilDwyer, Simon Van Eeden, Stephanie Van Eeden, Peter D. Hodgkinson, Alistair Smyth, David C. Sainsbury
Cleft Palate Craniofac J 2021 Jun 10:10556656211021700. doi: 10.1177/10556656211021700. Online ahead of print.

Sophie Butterworth
David Sainsbury
November 2022
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Cleft Collective_CDG_UpdateReport_May2023

1 The Cleft Collective Cohort Studies – Update Report for Cleft Development Group
May 2023

Overview
• Funding and amendment to extend the study – Our amendment to ethics and HRA (Health Research Authority) has been submitted and approved. This extends the study until September 2027 and will allow us to continue recruitment and follow up existing participants into adolescence. We are extremely grateful to each of the cleft teams for their continued support of the study, in particular for the procedures put in place to facilitate recruitment. This is vital to the study to ensure we maximise the sample size over the next five years, which in turn will facilitate research with large datasets which has previously been, at best, difficult to carry out, and at worst, impossible.
• Recruitment to the birth cohort is continuing at 15 of the 16 recruitment sites. One site is not recruiting due to a lack of research nurse time. The CC (Cleft Collective) and the PI (Principal Investigator) are working with the site's R&D (Research & Development) team regarding this. Total numbers for recruitment are 10551 individuals from 3770 families across both the birth and 5-year-old cohorts.

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	• Recruitment to the speech sub-study is improving but still behind pre Covid levels. As previously mentioned, we are now recruiting children up to age 36 months. Total numbers for recruitment are 1037 individuals from 520 families. • Genotyping is ongoing and over 7000 individuals have been genotyped to date. A new post-doc research associate has been recruited to continue our work on this, with funding awarded to Professor Sarah Lewis from the MRC (Medical Research Council). Additional projects using the genotyped data are in preparation. • Proposals to access and use the data continue to increase with 52 in total (see below for those submitted since last meeting). • Data sharing with CRANE (Cleft Registry and Audit NEtwork) is enabling us to validate cleft type for both the Cleft Collective and CRANE. We plan to submit a paper for publication detailing this work in 2023. Following new governance procedures for CRANE, we are unable to access five-year audit data direct from CRANE. However, we have discussed with CRANE a process for accessing five-year audit data direct from regional centres and hope to start this process in the next few months. • At CFSGBI (Craniofacial Society of Great Britain & Ireland) conference, we presented 9 papers (5 oral papers, 4 posters) as well as one general Cleft Collective update presentation. We also presented at seven CEN (Clinical Excellence Network) meetings with a particular focus on encouraging use of the Cleft Collective resource and clinician contributions to the forthcoming 15-year questionnaire. • The MRC funded study to use Cleft Collective data to identify children most at risk of mental health needs has started. A Research Associate has been employed to work on this. Data collection • Our return rates for questionnaires have increased from 50% to 55%for our baseline questionnaires while there is a consistent 39% return rate for our follow-up questionnaires. • Surgical form return rate for first surgery is 96%, though for many sites it is at or close to 100% for first surgery. We have been in touch with one of the two sites whose return rate was below 90% and have had success with them in increasing the returns. • We are keen to increase the return rate for second and subsequent surgical forms. We welcome attempts by teams to determine how they can increase the return rate for these forms and are happy to assist you in any way we can. • Return rate for speech sub-study o LENA (Language Environment Analysis) recordings - 85% (344of 407 returned) o18/24-month assessment form - 91% (433 of 477 returned) o36-month assessment form - 73% (323of 445 returned) • An amendment has been approved for changes to the online survey of speech and language therapy intervention to alter the process for requesting input from community teams. We are now waiting on updates to our database in order to start data collection. • We have recruited a field worker who will work with sites to collect missing data, including phenotype data, and will also liaise with sites about the process for collection of five-year audit data. New proposals since November 2022

CC048 Evie Stergiakouli, Improving mental health outcomes in children born with an orofacial cleft: Identifying children at most risk to target clinical provision

CC049 Nitisha Narayan, Exploring the prevalence of Faltering weight in Cleft lip and palate

CC050 Lucy Southby, Understanding the impact of the COVID-19 pandemic on speech and language development in children born with a cleft.

CC051 Mia Hart, Is there an association between maternal and paternal alcohol consumption in the risk of cleft?

CC052 Anni Christou, Mother's health and medication use during pregnancy and orofacial cleft

Information on all the proposals which have been approved is available at Approved Projects | Bristol Dental School | University of Bristol

Cleft Collective team
May 2023

Bristol Cleft collective(CC):
YW: I sent a report for the cleft collective but there are 2 quick things to pick up from that because they're time critical - CC have asked for suggestions for the 15 Year Questionnaire that is being developed at the moment and YW will share the link for this following this meeting. CC have had one suggestion so far from a surgeon, and CC would encourage suggestions from other clinical groups who have strong ideas about what should be included.
-The other point is that a field worker has been appointed who will be in touch with each of the cleft sites to arrange a visit to collect missing data and who will also liaise about collecting 5-year old audit data. YW thanked CR for suggestions on how this can be done most efficiently.
YW updated CDG about the programme grant that was submitted and has been successful. She thanked those who had been involved as co-applicants, collaborators and possibly as reviewers. This programme has come out of a desire to repeat Cleft Care UK when the children are older, and from work done with PPI and patient engagement work and chimes with what was said earlier from GPs report and AYs report and she therefore thinks that this is very timely. The title is: *what variations exist in unmet needs in young adults born with cleft, and how should these be addressed?*
There are four work packages, and there is one which involves clinics. It is and this aspect that YW needed to discuss with CDG. YW proposed visiting all the teams and shared with the group that she already had one visit arranged and provided dates of her availability over the summer. She proposed meeting with the CD of the team and will discuss who else from the team needs to be there with the CD.
SvE thanked YW and informed CDG that he would send the written CC report out to CDG after the meeting.

NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies:
SK: has provided SvE with the CSG report and she apologised for the late provision of this. SK informed CDG that the CSG is still meeting twice yearly virtually and are having ongoing discussions (which were raised last time) about the funding for admin support for the CSG as well as discussions about having all

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	the cleft research housed on the craniofacial society website so that everyone can see what's going on research wise in the country. CSG also has a meeting with the Royal College of Paediatrics and Child Health about future funding opportunities and for paediatric research in the country that will be funded by NI HR as well as their current and future strategies. If anything comes out of that that is relevant to colleagues, SK will circulate this to the CDG via SvE. **Cleft and Craniofacial Conditions Clinical Studies Group (CCC CSG) Update:** The CCC CSG provides an important service to the cleft and craniofacial clinical research community by supporting high quality research and supporting the work of the Cleft and Craniofacial Early Career Research Group (ECRG). **Research Update** The CCC CSG has the highest research output of all of the CSGs in the Children's CRN. Evidence of completed and current studies are included in Supplementary Tables 1 and 2. (Note: Many of these studies will have progressed since being added to the register, and an annual update will be compiled in April 2023). **Future of the CCC CSG** The CSG have continued with virtual-only meetings and have met twice in 2022, with administrative support provided by the NIHR CRN which will last until the end of 2022. This will cease from the beginning of 2023. All members of the CCC CSG continue with their role in a voluntary capacity. We have submitted a proposal for funding for an administrator for consideration to the Craniofacial Society of Great Britain and Ireland, and are awaiting the outcome of that discussion. **Proposal for an Online Register of Cleft and Craniofacial Research in the UK** The CCC CSG has also submitted a proposal to the CFSGBI to consider hosting an online register of research of cleft and craniofacial research in the UK. The CCC CSG currently have a nucleated critical mass of cleft and craniofacial research that is submitted for review. This is held in our Table of Studies (see Supplementary Tables 1 and 2). However, this does not reflect the true depth and breadth of research within the UK. Our proposal is that the CFSGBI as part of its website host an online register where people submit the basic details about their studies so that all members of the cleft and craniofacial research community can see current research. This would be similar to PROSPERO where systematic reviews are registered. This could be a very basic online form to complete. There could also be an option for people to then click on a link to a form to submit a study for further review from the CCC CSG should they wish. The CCC CSG are willing to moderate this list, however we propose that the CFSGBI host this centrally on their website. Kind Regards Sarah Kilcoyne Chair

	Cleft and Craniofacial Conditions Clinical Studies Group Appendix 1 – Background Information about the CCC CSG and ECRG • The CCC CSG is comprised of: o Cleft and craniofacial MDT clinicians o PPI representation from CLAPA, Headlines and Microtia UK o Representatives of CRN: Children o Cleft and Craniofacial Early Career Researchers Group o Senior Researchers in the fields of cleft and craniofacial conditions • The CCC CSG is responsible for: o Helping clinicians and researchers develop research proposals o Assess study feasibility o Provide expert advice o Ensure patient representation in all activities o Direct applicants to funding advice and funding opportunities o Facilitating collaboration or links between researchers with similar interests • Submitting research proposals to the CSG is an ideal way to engage with the NIHR process that may eventually fund the research. • Provides an opportunity for feedback from the committee to improve research design. • This system will help to nucleate a critical mass of high quality craniofacial and cleftrelated research work. • Patient representatives of the CSG offer their input to all studies. • The CC CSG currently has the highest output of research compared to any of the other 5x CSGS in the Children's CRN. • The CC CSG previously met twice a year in person in London face to face. During the pandemic we have changed to virtual meetings. Early Career Research Group • Research skills require specialist training. • The ECRG is for clinicians at any point of their professional (clinical) career who would like to develop their research knowledge, skills, activity and networks and potentially pursue more formal research training or funding.' • This group provides invaluable CPD, networking and collaboration opportunities to develop and future-proof cleft and craniofacial research and researchers in the UK.' • This group provides invaluable CPD and networking opportunities to support the next generations of cleft and craniofacial researchers in the UK and help build collaborations. • This specialist training and support is vital for succession and continued growth in research in cleft and craniofacial conditions. • The ECRG previously received funding for CPD, travel to London and catering for lunch for two meetings a year. • This funding was also lost with the withdrawal of funds from ScarFree and CFSGBI. • We would propose funding 1 face to face meeting a year, travel and catering for the ECRG to continue this important work. See **Appendix C: Research Updates – Appendix 2** **Early Career Researchers Group (ECRG)**

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	DS: ECRG had a meeting at the Cleft conference, and it was great to see representation from nurses and psychologists. There are few more projects to think about from the ECRG it looks very positive
12. Quality Dashboard	QD there was nothing to discuss. The QD remains as a standing item on the agenda
13. CFSGBI Feedback	MB introduced herself and her role as the new president of the craniofacial society and she congratulated HR on the recent successful CFSGBI conference in Cardiff. She confirmed that she has taken over the CFSGBI presidency from HR, but reported that the CFSGBI presidency is going through a period of transition and that HR and her were going to meet to do a handover; HR is going to chair the virtual AGM, which is on the 6th of June. MB encouraged CDG to add this date to their diaries. The last Council meeting was held on the 14th of March. Members of the society have access to the CPCJ Journal as part of their membership and this can be accessed through the website. As far as members of Council are concerned the demitting members are Lisa Crampin and Felicity Mehendale; GT has been co-opted on as the surgical representative in place of Felicity Mehendale. CFSGBI is working closely with light media and Matt Fell to hopefully implement online voting on the website which, should be useful for future meetings. MB urged CDG to support the next conference in Manchester in 2024 as there were a few centres that didn't have many, if any, delegates at the meeting this year and for the conference to be sustainable high attendance is needed.
14. Training	Cleft Training Interface Group (TIG) Fellowships: LF confirmed that TIG has now moved to post CCT, which is going very well. Interviews were held in January, and were a very high standard and one TIG fellow was appointed and they start their cleft TIG training in October, 2023. LF asked CDG to consider to the following issues: the first is: how the TIG is maintained as the gold standard for trainees now that it has~~'s~~ moved to post CCT training and the second is about trying to tailor the number of TIG fellows appointed to potential available consultant cleft jobs. LF reported that there had been a bottleneck of TIG fellows looking for consultant jobs for the last few years and questions have been raised about ~~whether or not~~whether TIG fellow appointments should be paused. She and the TIG committee feel that the downside for not appointing a minimum of one TIG fellow a year is that cleft then goes off the radar meaning that people interested in cleft then go and do a non-TIG fellowship or an overseas fellowship. If a TIG fellow was appointed at the next round of interviews, it would mean that it is possible that there would be three~~3~~ TIG fellows who might not find a cleft consultant job. The TIG committee would like to know what CDG thought about this and LF asked that with Cleft TIG fellowships now being post-CCT is there less of a responsibility to train them? VB felt that the TIG fellowships provide both the gold standard for cleft training and a level playing field with TIG fellowships being open to all the relevant specialities whereas non-TIG fellowships often are not and tend to be speciality specific. VB went on to say that not all those trained to do cleft will necessarily get a job doing cleft. CR concurred with VB and supports the competitiveness and transparency of the TIG interview process. He agreed with LFs suggestion that at least one TIG fellow is appointed per year. He even suggested using all the funding to appoint more than 1 TIG fellow a year and it is then up to candidates whether or not they wish to apply in the knowledge that the TIG fellow training post won't necessarily lead to a substantive cleft consultant job;

	he feels that the skill set that they will get during the Cleft TIG fellowship is transferable within other areas of head and neck practise and working in the wider cleft MDT whilst a TIG fellow is also a very transferable skill. He re-iterated that he felt it was up to the individuals applying and that the TIG process should be maintained and should be supported. SvE agreed and emphasised that the TIG committee provides the national quality assurance for cleft training, which might not necessarily occur in non-TIG fellowships. LF: In view of this agreement to continue to appoint at least one TIG fellow a year she made plea to the CDs to think about whether they can accommodate the next TIG fellow and to start letting her know as soon as possible so that she does not have to chase CDs for this information because TIG can only appoint if there are units willing to take on and train a fellow . SvE thanked LF for her report and asked the members of CDG to contact LF if they have any further thoughts about the Cleft TIG as he felt it important to get views from across the country and from all specialities..
15. AOB	The only issue raised under AOB was raised by SvE and it was to inform CDG that his term as CDG chair will end after the next meeting in November as he has now served 6 years as CDG chair. He urged CDG to think about his replacement and to send nominations to him before the next meeting. He thanked CDG for their support and shared that he had had a fantastic run and that he had enjoyed serving in the role. CDG members thanked SvE for his time as Chair. A short discussion followed about the next and subsequent meetings and it was agreed to continue with virtual meetings bi-annually but because of the full agenda and the failure to get through all the agenda items today it was agreed to extend the meeting from 4 to 5 hours. **Action 12/05/23:15.1:** CDG members to send nominations for the new CDG chair to SvE before the next CDG meeting.

The next meeting of the Cleft Development Group will take place virtually on Monday 27 November 2023 (9am-2pm).

Actions from Cleft Development Group meeting: 12th May 2023	Owner	Due Date
Action 12/05/23:3.1: AP will talk to Harry Lewis after the meeting and provide CC with information on how people affected with cleft across the UK can access information and be supported by nationwide organisations when cleft service is managed locally?		
Action 12/05/23:3.2: There seems to be a disconnect between the proposal, the current actions, and the involvement of patient and public voice. AP is going to speak to the engagement team and NHS England about the signalled impression of disconnect between the proposal, the current actions and the involvement of patient and public voice, and update CC and AS.		
Action 12/05/23:8.1: The CEN leads and the CDs will go back to their groups and teams to see if there were any willing volunteers to sit on this group and that this could be finalised at the next meeting.		
Action 12/05/23:9.1: Reasons of variability of outcomes in speech and dental outcomes across the country will be discussed at the next QMIC meeting		
Action 12/05/23:15.1: CDG members to send nominations for the new CDG chair to SvE before the next CDG meeting.		

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Appendix A: Cleft Centre updates.

Appendix 1: Update by Newcastle Cleft service

Newcastle Cleft report for CDG 12/5/23
Sorry for the late posting – I've just got back from a mission to the Philippines and have been ill for a few days.

Newcastle Cleft Team continues to keep up with targets in all areas. There remain some adult long waiters but these numbers are quite small. Our main problem is with our waiting list office which is failing and causing us scheduling problems. Our cleft nurses are fabulous at supporting our primary surgical planning.
Theatre throughput remains down for very unclear reasons post-COVID and the children's hospital remains tight for beds.
Our staffing remains stable although we note that Steph van Eeden is about to leave us to continue her successful research career in a University post. Steph has been a fabulous colleague and we wish her every success but are very sad to see her leave our clinical team and hope that we can continue to have strong research links with her.
Our team meetings continue to be remote, largely to help people attend and we find that we get through a lot more work.
We are working to reintroduce F2F Middlesbrough clinics although to a different pattern to how they were originally set-up. Our DNA rates to Newcastle from other distant areas remain lower than they were when we travelled to do the clinics locally.
Newcastle Hospitals has just undergone a major restructuring. We are now in a Board that includes amongst others the Dental Hospital. I am hopeful that this may be beneficial but can see other little advantage to it.
I have approached our Trust Business department in relation to the changed funding/commissioning arrangements. Their response suggested to me that they hadn't understood some of the ramifications of the document so this is a work in progress.

Appendix 2: Update by Leeds Cleft service – there was no update from the Leeds service

Appendix 3: Update by Northwest, Isle of Man and North Wales Cleft Service

Staffing

Nursing

Appointed a cleft CNS to a 1 year secondment as lead nurse. 1 CNS retiring at the end of May, vacancy to be advertised.

Paediatric Dentistry

Accumulated a back lot of paediatric dental patients in Manchester. Proposal for a fixed term specialist / speciality dentist 1 day a week to support the consultant paediatric dentist / dental therapist not yet approved by Trust.

Orthodontics

Consultant appointment in Wales has eased pressure but vacancy in Lancashire is impacting on local care for cleft patients.

Admin

Introduction of Epic EPR in Manchester has significantly reduced the admin staff workload but increased the admin burden on clinicians. Vacant secretarial posts to be converted to a full time assistant coordinator / speech therapy admin post and part time data clerk for the Network.

Clinical Director

The Network's Clinical Directors are appointed for 3 years with the option to extend for a second 3 year term. The current CD's 2nd term is coming to an end in the summer so we anticipate appointing a new Clinical Director

following interviews in June.

Other
No current staffing issues with psychology or SLT

Surgery
Manchester - Reduced access to the theatre, average 3 sessions per week (pre Covid 4.5 sessions per week), up to 50% cancellation rate due to bed / staff shortages / microscope availability - dependant on neurosurgery / ENT microscope availability pending replacement of old cleft microscope that became beyond repair 3 years ago. Effectively functioning at 30% of pre Covid lists. Primary surgery still at upper end of or just outside Quality Dashboard timings, palate repairs largely by 12 months but some are over 13 months, lip repair mostly just over age 6 months. Speech surgery wait time up to 12 months, ABGs appropriately prioritised / surgery before canine eruption although timing it at upper limits in terms of dental development. Manchester surgeons working together effectively to ensure that a surgeon is available for all available paediatric lists. Alder Hey continues to offer lists to the Manchester surgeons when the Liverpool surgeons are on leave which together with reduced cleft births in the region has helped to mitigate some of the impact. CD / Network Manchester have a meeting to discuss issues with the surgical directorate manager at RMCH next week, impression is that the directorate seems to target cleft for cancellations over other specialities due to 78 wait week priorities. 12-18 month wait for Adult surgery including orthognathic although trying to prioritise orthognathic now that longest waiters have been addressed.

Liverpool - paediatric lists as pre Covid, operating to Network protocol. Access to regular adult lists has improved. Orthognathic waiting time acceptable and other secondary surgery waiting time reducing.

Network's good performance at Liverpool masks poor performance at Manchester for CLP03/04 in SSQD.

One of the Network's surgeons is planning to retire in April 2024.

Births
Cleft births in the Network remain significantly reduced compared to the 10 year average which has been a trend over the past 3 years/ Only 10 births in Manchester, 16 births in Liverpool so far in 2023.

Appendix 4: Update by Trent Cleft service
Surgery

- primary surgery - well within standards now - primary lips being done at three to four months, primary palate surgery generally at 7 to 9 months
- speech surgery, again waiting lists very much under control.
- alveolar bone grafts: there is a one year waiting list of a year meaning that when patients they get to the top of the list they need repeat X-rays
- for adult surgery there is still a waiting list (LB does not know how long this is) but it is getting smaller.

Staffing

- Nursing team is up to full staffing.
- Speech and language that therapy team is very stable at the moment.
- Orthodontics were about to put out an expression of interest for our lead orthodontist as Melanie Stern's going to be retiring in the foreseeable future.
- Paediatric dentistry we still have a business case to extend our paediatric dentistry.
- Psychology things are much better now than they ever have been in Trent. There is one whole time equivalent and we're currently advertising for a further .5 whole time equivalent.

In addition succession planning is becoming a topic in our region as there are a number of members of the team approaching retirement.

Appendix 5: Update by West Midlands Cleft service

Staffing

Surgery

- Neil Brierley was appointed to a consultant surgeon post in January. Kezia is on maternity leave - Hannah John is covering her maternity leave for 12 months.
- Orthodontics Rachel Willis has been appointed, but we are still an orthodontist short. KK asked CDG members to please get in touch (particularly as the adult orthodontics is on the risk register) if they know any budding orthodontic trainees interested in cleft.
- Psychology: the adult psychologist service which is provided by the mental health service at the QE has been withdrawn so in response to that they have stopped seeing new adult referrals to try and put pressure to get someone else appointed.
- Speech and Language therapy: They are on SLT short and they are actively working on recruiting to this post.
- Administration: There has never been a data person to manage there data meaning that they are a CRANE outlier particularly for consent? This has been an issue because they have had a lot of change in administration staff and they have had difficulty retaining staff but this is something they are trying to address.

SvE: Advised KK to use the data that Crane supplies as a means to engage and get managers on board because the letters about outlier status will go to the medical director and the chief executive of the trust.

Surgery:

Operative capacity has slightly increased since December/January meaning there is proportionately have a slightly more access to paediatric operation lists. There is disparity between different surgeons waiting times (KK has the longest) resulting from previous prioritization of cleft patients over others meaning that there are now long non-cleft waiters that management is pressurising surgeons to address.

There is a constant balance that needs to be struck between primary and speech surgery and the wait for speech surgery is more than a year currently. They are trying to address this amongst the cleft surgeons.

Adult capacity is still restricted as they have limited access to the adult meaning that the waiting list is more than a year for any kind of rhinoplasty surgery.

Appendix 6: Update by Cleft Net East service

- Staffing updates

  I'm new to the clinical lead role and already facing some challenges with staffing.

  Network Manager – Welcome to Nathan King who has been seconded for a year to replace Mary Bance who is undertaking a new role in women and children's service.

  Psychology - poor staffing levels and currently recruiting for 1.4 WTE but as yet despite posting 5 times for 2 PT psychologists, we have had little interest and not been able to recruit a suitable applicant. The impact of this is no Psychology support in any clinics and a lengthy triage process with longer waits for patients to be seen following referral and issues not being picked up face to face in clinics.

  SLT – Lucy Southby will be leaving us on the 23rd May and Ali Birch and Catriona Larham will also be leaving us at the end of May following a seconded period covering Maternity leave. George will be returning in June but on a reduced contract. A business case has been submitted to increase the lead SLT posting but as yet there has been no interest in the post and as such the post has been revamped offering flexible hours in an attempt to make it more appealing.

  Clinical Nurse Specialists – We are currently at full capacity but will shortly be going out to recruitment as one of our CNS's will be leaving in July to focus on a personal business venture.

  Dentistry – Jackie Smallridge will be leaving us later in the year taking retirement. A business case has been submitted with a proposed 8 PA's per week. Currently Jackie has 4 PA's, but due to increased

waiting lists and the lack of community dentistry support 6 PA's have been indirectly agreed, but hoping for this to be increased.
Audiology – Some issues with getting children seen locally in some spoke hospitals due to capacity which adds pressure to the one day a week we are currently funded for.
Surgeons – 3 full time Surgeons with 2 part time surgeons in post.
Kana has returned from Maternity leave and working hard to reduce her large primary waiting Lists and currently we are getting a list a week for her.
Due to Strike action, BH and other factors this has hugely impacted on access to regular lists for some of our other surgeons although on the whole our access to lists have improved but we are not quite back to pre-Covid numbers, despite an increase in our birth numbers over the previous 12 months (2022 – 88 babies).
We are currently running at 11 lists over the service per month but unfortunately due to the reasons listed above lose the odd session over the month.
Admin – Full complement of admin staff with the recruitment of a spoke secretary to manage the spoke clinic lists. The Addition of the Spoke secretary has allow us to mop up those patients lost to the service or missing as this was identified and logged on the risk register. This has hugely improved and the numbers of missing patients/lost to service has significantly reduced. Our Admin team have also completed GCP to support collection of CRANE consent. We will be losing Our Speech Admin assistant in September who will be off to University to undertake his SLT degree and we have a secretary going on Mat leave in July. We will however see the return of Jenny another secretary returning from Mat leave later in the year.

- Primary Surgery Status
    a. Primary lip surgery
    Up to date – 2 children waiting over 6 months, due to need for other more pressing surgery/ongoing complex issue, and not appropriate for surgery
    b. Primary palatal surgery – As above 2 children delayed due to poor engagement (safeguarding).
    c. Alveolar bone grafts - 38 waiting with no date offered

- Secondary Surgery Status
    a. Speech surgery – Still trying to tackle our speech surgery waiting list
    b. Orthognathic surgery – 2 on the waiting list need dating
    c. Lip/Rhinoplasty surgery – Some long waiters but gradually reducing the numbers.

- Current Risks/Threats to Service Delivery

Ongoing issues with Dentistry and long waiting lists – reported and added to the risk register.

Numbers of cancellations almost weekly of children having primary and secondary surgery, due to poor health/URTI, on our surgical lists – difficulties with repeated cancellations for some children. Identified poor support from Local teams to monitor the well-being of children- paediatric and anaesthetic reviews- Inability to review children face to face by anaesthetic team due to capacity/not part of Job plan/inadequate numbers of paediatric anaesthetic consultants for reviews/No additional clinic space and time etc.
Reintroduction of a Face to face Pre-assessment by CNS to assess and create a pool of children, who can be added into lists at short notice rather than lose slots on theatre lists.

Other staffing news – there are likely to be further retirements announced before the end of the year, which are not yet public knowledge, which will impact further on our service.

Appendix 7: Update by North Thames Cleft service

- There has been a large backlog of patients requiring cleft MDT appointments. Work has been undertaken to modify relevant protocols to rationalise the need for MDT review, to help address the backlog. Improved but not resolved.
- Waiting times for alveolar bone grafts and osteotomies are now essentially back to normal. 2-3 month wait for ABG once listed and 2-4 months for osteotomies once listed.
- Sufficient capacity to treat all primary clefts within the defined Cleft Dashboard limits
- Large orthodontic workload increasing treatment times per patient.
- VPI assessments timescales much improved (6months down to 2-3).
- Psychology services are now provided on a referral basis only.
- Audiology services are now largely provided at local level.
- Paediatric dental reporting on CRANE still not happening with Consultant on long term sick leave and no junior staff.
- Recent report from CRANE identified negative outlier in CRANE consent, speech and Paed dent outcomes. Currently reviewing the data for this.

Staffing

- The consultant paediatric dentist role has not yet been appointed but interviews being held next week.
- Our long serving and dedicated lead in SLT, Marie Pinkstone will be retiring in June and will be sadly missed as she has been supporting the service for over 20 years! A replacement has been appointed.
- Following a mistake by the deanery in appointing a new orthodontic post-CCST trainee registrar the trust agreed the appointment of a 3 PA locum orthodontic post to fill this void.
- Currently have a band 8 cleft psychologist position available (the only one at Broomfield). Covered by temp staff, advertised but no-one has applied.

Appendix 8: Update by The Spires Cleft service

Staffing Updates

- Locum Cleft Maxillofacial surgeon, Juergen Schlabe, started in Oxford in January 2023
- New cleft co-ordinator, Claire Williams, started in May 2023 in Salisbury.
- Oxford cleft co-ordinator, Jade McKnight, currently on maternity leave with cover (Sandeep Bidla) expected to being once Trust clearance procedures completed.
- Currently succession planning for Oxford Cleft Orthodontist and Network Secondary-Orthognathic surgeon.
- Discussions ongoing regarding business case for a Paediatric Dentist for the Network.
- Job planning for a Restorative Dental appointment in Salisbury.
- Spoke orthodontic provision remains absent in Poole and Swindon.

Primary Surgery

- Pressure on elective paediatric beds and critical care beds persists at the Oxford Site.
- Total of 5 undated P2s across the service.
- Operating within KPIs for primary lips and palates and newly listed ABGs (although 12 patients across the network have waited for more than 52 weeks).

Secondary Surgery

- Awaiting speech surgery n = 37: Salisbury 26 (22 children); Oxford 11 (3 children)
- Awaiting lip revision n = 14: Salisbury 4 (3 children); Oxford 10 (2 children)
- Awaiting adult rhinoplasty n = 17: Salisbury 9; Oxford 8.
- Orthognathic surgery: 4 patients currently ready across the network; all dated.
- Salisbury site to explore mutual aid request from Bristol with regards to assistance with Palate Investigation Clinic and possible speech surgery cases.

Threats to Service Delivery

- Lack of GDP access for families remains a significant problem (cf. Tri-centre Audit)
- Nursing team finding accessing Community Dietician support for outpatients increasingly difficult
- Sustained pressure on Clinical Psychology waiting lists; impact of lack of local CAHMS support likely to be a factor.

Positive News

- First Network-wide Multidisciplinary Morbidity & Mortality Meeting held on 5th May.
- Network-wide Virtual Pre-Op Assessment Clinic for complex patients is proving effective.
- The Hunterian Museum has just re-opened at the Royal College of Surgeons of England; cleft surgery is now represented with a Spires cleft family being actively involved.
- Spires is having a team summer party on the 16th June and we can't wait!

Appendix 9: Update by South Wales Cleft service

- **Staffing updates**
  Locum cleft surgeon 7 sessions for 12 months, Serryth Colbert's appointment has particularly helped to address the adult long waiters for rhinoplasty and lip revision.
  Lead Consultant Clinical Psychologist 7 sessions
  Dr Aimee Pudduck, started in February 2023, replacing Dr Vanessa Hammond
  Band 7 Vacant- 6 sessions Speech and language therapy not yet signed off to go to recruitment but hoping to do so shortly. The 2 band 6 SLTs will return from Mat leave July and August 2023 respectively.
  Appointment of clerical officer for Speech and language therapy- 24 hours
  Hannah Gammon started on the 6th December.
  Appointment of clerk Band 2 for the cleft team 37.5 hours- Christina Edwards, started on 1st December.

- **Primary Surgery Status**
  a. We have not resumed all our pre covid lists; we consistently have 1 paediatric list per week however we are currently on top of our paediatric cases due to a slow birth year. The service continues to experience an increase in dental patients requiring extractions or gold chains and we are working with our dental community colleagues to look at the pathway to support these patients. We have given up cleft lists in order to undertake urgent dental work.
  b. Primary lip surgery- currently operating around 3 months
  c. Primary palatal surgery- currently operating around 6 months
  d. Alveolar bone grafts-after listing waiting 3 months for surgery

- **Secondary Surgery Status**

a. Speech surgery- Paed cases are treated 3 months from being listed whereas adult cases are not being treated for surgery in Morriston as priority continues to be given to cancer care. We currently have 9 adult speech surgeries waiting for Morriston, some of which have been waiting prior to Covid. Recently we have been able to request ad hoc lists and 2 lists have been given for May 17th and 30th May. We continue to flag these patients as a priority and have requested that these patients are treated in Singleton hospital with the enhanced recovery facility. Discussions are ongoing. We have a small number of dental implant/ABG cases also waiting with currently no options for surgery.
b. Orthognathic surgery- Two patients are currently waiting for dates on the Maxillofacial theatre lists.
c. Lip/Rhinoplasty surgery- The lists in Singleton are going well and by the Autumn 2023, we will have addressed the waiting list for lip revision and rhinoplasty.

- **Current Risks/Threats to Service Delivery**
  - Lack of theatre capacity for paeds requiring paed intensive care in Cardiff (one patient) and adult speech/implant surgeries.
  - Outpatient backlog- working through the backlog of 15-year-old patients, additional clinics have been arranged to cover this cohort and will be addressed this year. We are beginning to appoint 20 year olds.
  - Orthodontic waiting lists for treatment and delays for those in treatment. Currently there is a 4 and a half year waiting list for orthodontic treatment, this is impacting patient's care. The main issue is the lack of dental nurse support to run the clinics as well as room availability. This has been escalated to senior management and to the commissioners. Discussions are ongoing.

Appendix 10: Update by South West Cleft service

South West Cleft service May 2023 report for CDG

Overall
We cannot see how we can adequately recover without different engagement with Bristol Children's Hospital and different capacity available there. We have worked very hard to make all other options work.
We will be declaring that to our NHS Regional Commissioners and ODN next week
Increased workload and firefighting last year is depleting energy and morale in team and is no longer sustainable.

Relapsed capacity to operate
Now listing primary cleft palate repairs at 14 months or older
Even then that is at the expense of speech surgery. CLP children's alveolar bone grafting not done in Trust since COVID
Capacity issues in BCH theatres seen in all surgical specialties notably Cleft, Epilepsy surgery, Neuro and Cardiothoracics. All three specialties reported by media.
The decreased capacity is seen in number of elective lists but also decreased cases we are able to undertake on each list added to which we have backlogs. We are not back to precovid numbers of procedures we are able to undertake.
Adult capacity - we do not have precovid lists capacity back

Mutual Aid dried up before last autumn. We remain active in seeking help.
Derriford operating has been a great experience. Until my ill health ceased the service. I am still not able to operate. We are now seeing significant ABG failure rate which we are investigating. Until we know the cause of this our Derriford work remains uncertain.

Trust has arranged Peter Revington to return from retirement for ABG at local Spire private hospital.
Adult septorhinoplasty in private sector:
St Josephs south wales contract is ceasing
Nuffield contract continues as hoc.

HARM REVIEW
Submitted to Trust September 2022
It was a snapshot not a complete review of all cases
6 months later a Press release was made based on our Harm Review with amended figures.
New press release in preparation with original figures.
Meanwhile BBC and other media outlets have carried that story.

Duty of candour phone calls and letters are well underway
FTF appointments beginning
Seeing Second victim blaming - Angry feelings of parents in some cases against the cleft team is adding to the moral injury of the team who have done all they can to help support cleft service provision.

Trust is committed to fulfilling our recommendations in Harm Report
Including clinical and admin teams. This is very positive for a re-established service. We are very pleased.
But we have been made aware that unlikely new clinical accommodation can be achieved until 2025
I cannot operate currently after further work related spinal injury. I can be deployed to start to tackle our outpatients clinics backlog but we cannot find suitable accommodation.

Our biggest hurdle of insufficient operating capacity cannot be addressed in current capacity of children and adult hospitals.

Richard Thompson appointed as locum cleft consultant for 12 months starting June 2023.
But do not have any extra operating sessions for him.

ORTHODONTICS
We have split the lead role. Jules Scott is now joint Cleft Orthodontic lead for SWCS, covering Devon and Cornwall. Scott Deacon remains lead for Somerset, Bristol and Gloucester.
Cornwall has no NHS Consultant Orthodontist, Jules Scott is now driving to Truro to see Cleft patients.
Nikhil Gogna has started as locum Cleft Consultant orthodontist in Bristol seeing patients all day Friday.

Psychology
Lead retires September
Recruiting to this
Other roles now filled

CNS
Lead has retired
Locuming for us
Recruited to lead from within team

SLT
actively increasing SLT capacity
Still waiting for SLA to be agreed with UHP for SLT post unresolved for 4 years
NUGS used to mitigate in child and adult groups

Paeds dentistry
Devon and Cornwall has no paediatric dentistry consultant after incumbent left post.
SW at worst of UK shortage for children's dentistry.

Amy Hollis investigating other options including child friendly dental practices.

OVERALL
We continue to have twice monthly meetings with regional NHS commissioners and SW Paeds surgery ODN which has been very positive supportive experience. We are working with Trust about addressing harm review recommendations which will take time.
But there is nowhere else we can go now with service recovery with regard to operating opportunities.

Appendix 11: Update by Evelina London Cleft service

- **Staffing updates**

We have been through some changes and, as ever, there are more changes afoot. However, we have an almost full complement of staff in all clinical areas at this moment.

- Admin and Management

Our service manager is relatively new (October 2022) and still getting to grips with the role (having previously worked in community and never been involved in inpatient services inc theatre lists etc) and split between cleft and plastics. Our most recent assistant service manager (full time) has left (after just 6 months with us) and his replacement hasn't started yet. Our admin team is certainly the group struggling the most and this has a significant impact on the whole service. Morale is low and sick leave continues to be high – adding further pressure.

- Surgical Team

Our junior doctor / senior trainee / fellow situation seems to change rapidly and we are currently recruiting for a full time fellow (non TIG) and trying to make sure we have max fax ST and plastics FY3 cover too. Through job-planning, our 5 consultant surgeons will continue largely as before.

- Speech and Language Therapy (SLT)

This team is back up to speed now after maternity leaves, reductions in hours and sick leave. The establishment continues to evolve to accommodate various changes but we are fully staffed in terms of wte and the team are working really well.

- Nursing

Our lead CNS has moved to a new role as lead nurse for theatres in Evelina. During her time with ELCS, she has evolved the role and the directorate decided that our replacement lead CNS would actually be recruited to provide cover across Cleft, Plastics, ENT and other surgical specialties. This means her role in cleft will be largely managerial whereas previously we have had a full time lead cleft CNS in a clinical lead position.

- Psychology

This team were fully staffed and were pleased to have been able to cover the 1.0 wte band 8a team member's mat leave. However, the full-time band 7 has now resigned (not to discuss here, but there is a real issue with newly qualified staff staying very short times before being recruited to higher banded posts) and this will leave us with a short fall for some time. We have, however, been able to recruit a 0.6 wte assistant psychologist (band 5) who will start in June – this is a new post / a repurposing of other psychology establishment monies.

- Dental and Orthodontics

We are likely to lose some orthodontic time in the coming months and backfilling 2 PAs is challenging – we are looking at options to get back to full coverage. Our regional consultant orthodontists continue to be a great support to us and we highly value them. We have 3 Paediatric Dentists now – all part-time – and they are making inroads into our wait lists and collecting audit data at 5 etc. We have fantastic restorative dentistry support for some of our St Thomas' MDT clinics and there are treatment clinics provided at Guy's Hospital. We are in discussion at the moment about how to develop things further.

- **Primary Surgery Status**
    a. Primary lip surgery
    b. Primary palatal surgery

c. Alveolar bone grafts

We are on track to complete all primary lips and palates within the national protocols of first lip repair lip repair at 3-6 months (by 6 months) and palate repair 6- 12 months (by 13 months). Similarly, to our position at the last CDG meeting in Nov 2022, ABGs are a little more variable depending on the individual surgeon – one surgeon has limited access to paediatric lists and so his waits are longer. We have 37 children waiting for ABG. 21 of these have waited longer than 18 weeks but all appear to be being done before 52 weeks. We have 1 child who has waited 73 weeks but this is an issue with the family DNAing / declining etc and is being reviewed regularly. The need for extractions to be completed before ABG continues to be difficult and we are working to resolve this issue.

- Secondary Surgery Status
    a. Speech surgery
    b. Orthognathic surgery
    c. Lip/Rhinoplasty surgery

Secondary surgery is harder to quantify as it varies from surgeon to surgeon. We have fewer adult lists post-covid and two of our surgeons don't have their 'own' adult lists and are reliant on dropped or given over lists from colleagues – hence there are longer-waiters for these surgeons. But we have a plan to deal with this issue and make sure these adults get their surgeries.

For adult **speech surgery** we appear to now have 6 adult patients waiting having waited over 18 weeks and 1 over 52 weeks (this is a small increase from my last report). There are 8 children who have waited longer than 18 weeks for **speech surgery**, with 1 having waited 36 weeks.

For adults waiting for **lip revisions**, all but 1 are over 18 weeks but under 52 weeks. We have 18 adult patients waiting for **nose revisions** – 10 have waited over 18 weeks and 1 has waited over 52 weeks (but the reasons for this are known).

We now have only 2 adults who have waited longer than 18 weeks for orthognathic and none are breaching 52 weeks.

- Current Risks/Threats to Service Delivery

The move to the EPIC database has been delayed until 5 October 2023 but is still giving great cause for concern in terms of the impact we are expecting it to have on activity and service delivery …

We were forced to move to an ABCD timetable (repeating 4-week pattern rather than having 5th days of the month anymore) from 1 May 2023 and this has been a major headache. This was imposed by Evelina (Children's Hospital) but our adult hospitals in the trust (St Thomas' and Guy's) do not run on an ABCD timetable. Access to our theatre lists is proving challenging and we have reached an impasse with TAP (the theatre booking team) who simply cannot work out how to accommodate us. This is preventing us from booking adult lists beyond June at present.

The industrial action (nurses, junior doctors, agenda for change staff) has had a huge impact. Combined with the Queen's funeral, King's coronation and multiple bank holidays. PLUS, train strikes, teachers' strikes and tube strikes. All have this is having an impact on our RTT.

We have made some progress with our outpatient follow-ups but still we have some MDT clinics where there are up to 100 patients who are overdue their planned F/U appt. This is particularly problematic with audit time points ie patients may not be brought back to the MDT when they're in the window for age 5, 10, 15. If patients aren't appointed to a formal audit clinic (ie patients with complete bony clefts) then we risk missing these protocol assessments as well as the opportunity to see patients in a timely fashion. We are currently doing a

piece of work looking at how to redistribute or catch up around the region ie running extra clinics, virtual clinics, switching from doing one clinic to another where need is greater.

Appendix 12: Update by Northern Ireland Cleft service

NI Cleft Service Update for CDG meeting May 2023

Surgery – Chris still does not have full surgery/ theatre slots back which is impacting heavily on waiting lists for secondary surgery, 4 children waiting 2 years on Pharyngoplasty. 7 waiting for 12months +, a further 12 patients waiting 6 months or less. Primary palate surgery is still within 13 months. Fortunately after a lot of coercion we have been informed Chris will get his Monday surgery slot back in children's hospital from June which should reduce pressure.

There are over 60 adults waiting for cleft related surgery and 7 adults for speech surgery. Adults are operated on in Ulster Hospital and as of update last month there are no theatre slots in Ulster Hospital for Cleft.

ABG – (update provided by Mr Darren Johnston Consultant Orthodontist in NHSCT) The local ABG surgeon has now resigned his post but Tom O'Neill Cleft surgeon (Swansea) has been kindly coming over to Northern Ireland since July last year to enable this service to continue. Tom and I have now carried out 13 ABG outpatient clinics at Antrim and Tom has operated on 21 children (25 clefts) in 2022 and thus far 14 children (16 clefts) in 2023. We have now reassessed all of the patients that were on the SET waiting list for ABG (42 I understand) and are now trying to see the 50+ patients who were to get an initial assessment or review on an ABG clinic. Further outpatient clinics are planned for June but the Ulster is yet to confirm provision of June operating lists.

An orthodontic consultant post with a regional cleft orthodontic role was advertised in December but there were no applicants. We therefore don't have a permanent regional cleft orthodontist and have no local ABG surgeon. There doesn't appear to be any longer time plan for future provision of the ABG service which is clearly vulnerable as it currently relies on Tom and myself to keep it going.

General waiting lists – long waiting lists for MDT clinics and struggling to see 10/15 and 20 year olds.

Staffing – lack of Cleft sessions in Dental, Psychology and Surgery resulting in ++demands on service and long waiting lists.

Appendix 13: Update by Scotland Cleft service

- **Staffing updates**
    - Band 2, 1 WTE admin down.
    - Cleft CRANE Data Validator appointed.
    - Issue relating to consent (retrospective to add 2016 data)
    - Reviewing SLA with a view to further CNS/clinical assistant development within the service.

- **Primary Surgery Status:**
  Challenges gaining all lists. Slow increase in age of procedures. Presently just within CCS guidance (As dashboard).
    a. Primary lip surgery (4-5 months)
    b. Primary palatal surgery (10month)
    c. Alveolar bone grafts (< 3months from ideal)

- **Secondary Surgery Status**
    a. Adult waits slowly reducing. 50% reduction form 1 year ago. wait for surgery 12-18 months.
    b. Speech surgery (9 months)
    c. Orthognathic surgery (commenced Nov 22 see above)
    d. Lip/Rhinoplasty surgery (commenced May 22 see above)

- **Current Risks/Threats to Service Delivery**
    - Lists have become more regular and threat reduced.

Appendix B: CEN updates-written CEN updates received from the following CENs and Lead Groups

Appendix 1: Nursing CEN update (HS)

The cleft nursing CEN continues to build with enthusiasm as we continue with and beyond Covid, the utilisation of MS Teams has enabled peer communication and support to happen more frequently. Although the benefits of face to face meetings was most definitely felt and appreciated at conference in Cardiff.
Cleft nursing CEN hosted a day of education, updates and networking, with 26 attendees. The day incorporated presentations from current and past nurses, speech therapists, psychologist and charity sectors. Nursing were pleased and proud to be part of the conference particularly in supporting Helen Robson as President, as well as 5 papers being presented by nurses.
The National Cleft Course delivered through Anglia Ruskin University in Cambridge is now concluding its first cohort with written assignments currently being marked before external moderating. The dates for next year have been agreed with a start date in February 2024, the application process is expected to open in September 2023. It is again anticipated that a place will be offered to each Network in the first instance, this has been found to be beneficial to the students as they have thrived with the networking.
Nursing remains supportive if the SLUMBRS 2 Study which currently has an agreed 6 month extension. Networks continue to aim to recruit all eligible infants but the numbers eligible have been lower than expected with a number of cleft palate infants requiring respiratory and feeding tube assessments early in their care, this has been communicated to the researchers.
It is understood that a few nurses have expressed an interest in being part of the Early Researchers Group meetings and Nursing CEN is currently working towards establishing a subgroup for Innovation, Development and Evidence-based Practice (formerly known as the Audit Group).
Nursing CEN will also be continuing to offer members 2 meetings a year with an education, information and development element, the next is anticipated to be on October 2023.

Heather Sahunta
Lead Nurse and Chair for Nursing CEN
Trent Regional Cleft Network
Nottingham Children's Hospital

Appendix 2: Lead Cleft SLT group and SLT CEN (GP)

- Recent meetings

Lead SLT meeting: 9th May 2023
CEN Spring study day: 19th April 2023 (Cardiff) New chair, Sarah Kilcoyne

Upcoming Lead SLT changes:

- Northern & Yorkshire, Newcastle. Steph van Eeden moving to academic & teaching post at Newcastle University in August.
- CleftNet East. Lucy Southby, move to Senior Research Fellow in Speech and Language Therapy at Cardiff Metropolitan University
- North Thames. Marie Pinkstone retirement in June.

a. Ongoing programmes of work (Lead SLT group)

- Intervention (therapy) demand and capacity scoping
- Standardisation of recording and playback equipment for audit
- Reviewing audit outcome data and National Standards, prioritising data

completeness

- Cleft collective speech & language study and Intervention questionnaires

b. Planned programmes of work

- 2023/4 Resuming external consensus listening for audit
- Work with CRANE to explore factors in variability of speech outcomes (potential for risk adjustment)
- Updating of cleft speech information for Royal College SLT guidelines and website

c. Issues to be discussed/raised at CDG

- Impact of commissioning changes
- CRANE registration for patients with SMCP

- Planned meetings

Lead SLT meetings
July 11th 2023
September 11th 2023
November 14th 2023

Appendix 3: Paediatric Dentistry Clinical Excellence Network Update (JM)

- Recent meetings 19th April 2023 – face to face
  a. Speakers: Muthu Murugan and Nicola Innes from Cleft without Caries research and working group, very insightful presentations about alternative means of preventing decay or accessing paediatric dental care early within LMIC and current data available about decay in children born with clefts. The group felt they had collected a lot more data over the last 20 + years which could add significant weight to the current evidence base.

  b. Ongoing programmes of work
     i. Dental deserts project, questionnaires to be completed by all parents of children aged 0-16yrs on ability to access local dental care for their child.
     ii. Enamel hypoplasia in primary molars – NW regional data presented at CFSGBI conference 2023, now collecting from other units
     iii. Burden of dental care in cleft children – CNE presented CFSGBI conference 2021, now collecting national data on number of appointments and travel times
     iv. 3 x papers submitted to BDJ series on cleft to be published later this year
     v. Online access to calibration through CFSGBI website – we have approached British Society of Paediatric Dentistry to part fund this and it is looking promising.
  c. Planned programmes of work
     i. Utilisation and publication of 20 + years of dmft data and trends within the data
     ii. Further discussion and analysis of the Developmental Defects of Enamel data collected by the CEN for the last few years
     iii. Collation of leaflets to publish a national leaflet on dental care for children born with clefts and/or a video to go on the website with oral health advice
  d. Issues to be discussed/raised at CDG
     i. Ongoing problems with access to local NHS dental care for children, may be able to negotiate further with more local commissioning. This is creating longer waiting

times for consultant/specialist care within cleft hubs. We have also looked at allocation of sessions for paediatric dentistry across the UK in relation to numbers of births per unit and activities carried out by paediatric dentists in each unit. There is large variation across the UK.

- Planned meetings

Virtual meeting November 2023

Appendix 4: OCEN update (JS)

- Membership has grown with new Consultants and Trainees

- OCEN leads meetings continue quarterly

Themes

  - Reduced access to dental care
  - Delays in dentoalveolar procedures, ABGs, adult surgery

OCEN working with Liz Jones from GIRFT to help support this

- Face to face meeting in Cardiff
  - Ongoing pilot looking at use of PAR in cleft as an outcome measure stratifying by cleft type
  - Ongoing data collection at age 5, pre-orthodontic treatment and post orthodontic treatment
  - Joint meeting with Orthodontic and Surgical CENs.
  - OCEN working group working with Cleft Collective with the aged 15 year questionnaire

- Continue meeting face to face in Spring and virtual CEN meeting in autumn
  - Additional Cleft session facilitated by OCEN at the British Orthodontic Conference to raise profile of cleft orthodontics

Appendix 5: Surgical CEN (GT)

- Recent meetings

Face to Face meeting 19/4/23 Cardiff

It was great to have a face to face meeting! Very good turnout.
We also combined with the orthodontic CEN for 1 hour (standing room only) for discussion of growth measures and views on publishing identified outcomes.
Clinical discussions on ABG, cleft nasal surgery, and approached to extremely wide palates.
Updates from multiple other groups eg Headlines, CLAPA, Cleft Collective.
Initial discussions about cleft service spec updates – presented by Simon.

Virtual Meeting 21/11/22
This included updates from CLAPA, CRANE, TIG etc. There were also a number of topics discussed. The format is a combination of business meeting with educational topics. There was again good turnout with almost 40 attendees.

a. Ongoing programmes of work
b. Planned programmes of work
c. Issues to be discussed/raised at CDG - nil

- Planned meetings

Next Virtual Surgical CEN Meeting TBC in November

Appendix 6: Ent/Audiology CEN

Recent Meeting: Wed 19th April 2023.

Presentations by Cleft Collective, CLAPA and Crane.

Projects:

- Election for existing and new member roles to help with the administration / work of the CEN. To include
    - Communications Office – help with CLAPA and other online resources eg CFS website.
    - Publications Officer: Keep group updated on new relevant publications: to promote discussion / agreement across sites.
    - Research co-ordinator: collect and collate multicentre data, to aid CEN publications. Review Cleft Collective information to inform CEN on possible future projects / research ideas.
    - CRANE Co-ordinator: to discuss CEN views with CRANE and help with our presence in the database development
    - New Chair / Secretary
-
- Finalising SoP for access to CRANE to check names in denominator for annual QD data submission.
-
- Development of proforma for data collection for entry onto crane – agree for 5 year old data. To be discussed further for NBHS, as data presented to CEN by CRANE had some points that needed clarification.

Appendix C: Research Updates

Appendix1: The Cleft Collective Cohort Studies – Update Report for Cleft Development Group
May 2023
Overview

- *Funding and amendment to extend the study* – _Our amendment to ethics and HRA (Health Research Authority) has been submitted and approved. This extends the study until September 2027 and will allow us to continue recruitment and follow up existing participants into adolescence. We are extremely grateful to each of the cleft teams for their continued support of the study, in particular for the procedures put in place to facilitate recruitment. This is vital to the study to ensure we maximise the sample size over the next five years, which in turn will facilitate research with large datasets which has previously been, at best, difficult to carry out, and at worst, impossible.
- *Recruitment* to the birth cohort is continuing at 15 of the 16 recruitment sites. One site is not recruiting due to a lack of research nurse time. The CC (Cleft Collective) and the PI (Principal Investigator) are working with the sites R&D (Research & Development) team regarding this. Total numbers for recruitment are 10551 individuals from 3770 families across both the birth and 5-year-old cohorts.
- *Recruitment* to the speech sub-study is improving but still behind pre Covid levels. As previously mentioned, we are now recruiting children up to age 36 months. Total numbers for recruitment are 1037 individuals from 520 families.
- *Genotyping* is ongoing and over 7000 individuals have been genotyped to date. A new post-doc research associate has been recruited to continue our work on this, with funding awarded to Professor Sarah Lewis from the MRC (Medical Research Council). Additional projects using the genotyped data are in preparation.
- *Proposals* to access and use the data continue to increase with 52 in total (see below for those submitted since last meeting).
- *Data sharing with CRANE (Cleft Registry and Audit NEtwork)* is enabling us to validate cleft type for both the Cleft Collective and CRANE. We plan to submit a paper for publication detailing this work in 2023. Following new governance procedures for CRANE, we are unable to access five-year audit data direct from CRANE. However, we have discussed with CRANE a process for accessing five-year audit data direct from regional centres and hope to start this process in the next few months.

- *At CFSGBI (Craniofacial Society of Great Britain & Ireland) conference,* we presented 9 papers (5 oral papers, 4 posters) as well as one general Cleft Collective update presentation. We also presented at seven CEN (Clinical Excellence Network) meetings with a particular focus on encouraging use of the Cleft Collective resource and clinician contributions to the forthcoming 15-year questionnaire.
- *The MRC funded study* to use Cleft Collective data to identify children most at risk of mental health needs has started. A Research Associate has been employed to work on this.

Data collection

- Our return rates for questionnaires have increased from 50% to 55%for our baseline questionnaires while there is a consistent 39% return rate for our follow-up questionnaires.
- surgical form return rate for first surgery is 96%, though for many sites it is at or close to 100% for first surgery. We have been in touch with one of the two sites whose return rate was below 90% and have had success with them in increasing the returns.
- We are keen to increase the return rate for second and subsequent surgical forms. We welcome attempts by teams to determine how they can increase the return rate for these forms and are happy to assist you in any way we can.
- Return rate for speech sub-study LENA (Language Environment Analysis) recordings –
    - 85% (344of 407 returned)
    - 8/24-month assessment form - 91% (433 of 477 returned)
    - 36-month assessment form - 73% (323of 445 returned)
- An amendment has been approved for changes to the online survey of speech and language therapy intervention to alter the process for requesting input from community teams. We are now waiting on updates to our database in order to start data collection.
- We have recruited a field worker who will work with sites to collect missing data, including phenotype data, and will also liaise with sites about the process for collection of five-year audit data.

New proposals since November 2022

CC048 Evie Stergiakouli, Improving mental health outcomes in children born with an orofacial cleft: Identifying children at most risk to target clinical provision
CC049 Nitisha Narayan, Exploring the prevalence of Faltering weight in Cleft lip and palate
CC050 Lucy Southby, Understanding the impact of the COVID-19 pandemic on speech and language development in children born with a cleft.
CC051 Mia Hart, Is there an association between maternal and paternal alcohol consumption in the risk of cleft?
CC052 Anni Christou, Mothers health and medication use during pregnancy and orofacial cleft

Information on all the proposals which have been approved is available at Approved Projects | Bristol Dental School | University of Bristol
Cleft Collective team
May 2023

Appendix 2: NIHR Cleft and Craniofacial Clinical Studies Group Table of Studies
January, 2023

	Studies through CSG			Previous Updates	Latest Update
	2014/2015				
1	PRS survey	Marie White and Felicity Mehendale Felicity.Mehendale@ed.ac.uk	Funded - BPSU data	Jan 2022: Presented at Craniofacial conference 2021 and submitted for Edinburgh 2022. Two presentations at International Robin Sequence meeting April 2022. Peer reviewed papers being written up.	Jan 2023: NO UPDATE
	2015/2016				
	Studies through CSG			Previous Updates	Latest Update
2	Speech processing and PSD in cleft palate	Lucy Southby lucy.southby@addenbrookes.nhs.uk	Funded NIHR for PhD	Jan 2022: PhD awarded. Systematic review published. Presented findings at ECRG meeting, to BCH SLT team and the ACPA, CFSGBI and ICPLA conferences. First main findings paper at full-draft stage and a second in preparation.	Jan 2023: IALP webinar panel presentation. I have also submitted a discussion paper based concepts discussed in thesis. Main findings still to be disseminated.

3	MRI and speech	Mattieu Ruthven and Marc Miquel matthieuruthven@nhs.net m.e.miquel@qmul.ac.uk	Bart's Charity	Jan 2022: Jan 2022: Apr 2021: Barts Charity funding secured (4-year duration) Sep 2021: work from second part of fellowship submitted for publication Nov 2021: • Start of Barts Charity funded project • Clinical Scientist recruited and started working on project Jan 2022: PhD student recruited and started working on project	Jan 2023: Oct 2022: PhD student successfully passed nine-month progression review Nov 2022: work from second part of HEE/NIHR fellowship (development of AI methods to automatically track the motion of articulators in images of the vocal tract) published (sciencedirect.com/science/article/pii/S1746809422007443) Jan 2023: work from third part of fellowship (development of AI methods to automatically segment the levator veli palatini in 3D images of the vocal tract) completed March 2023: • PhD student submitting abstract on latest work to leading Medical Image Computing conference (https://conferences.miccai.org/2023/en/) • In process of making the data used in fellowship and Barts Charity project open source
4	Hydrogel scaffold	Bruce Richard brucerichard@blueyonder.co.uk		Jan 2022: Post Doc started last year and has a new supervisor	Jan 2023: NO UPDATE
5	Aesthetic measure	Bruce Richard brucerichard@blueyonder.co.uk		Jan 2022: PhD student is half way through his study and is using our project data as the basis for his PhD. 2 Computer science Conference presentations on the algorithms. Started an International networking group for cleft facial aesthetic outcome. Involving interested clinicians and academics in computing and visual science etc. Chair is David Sainsbury. No Big grant success yet!	Jan 2023: NO UPDATE

6	Assessment of infant models – data mining	Bruce Richard brucerichard@blueyonder.co.uk	Funding application to GOSHRF VTCT grant for £17,000 and Welsh research grant of £5000 to pay for the computing aspects.	Jan 2022: Very slow progress. As the PhD student had issues and only started in March for 3 months and then nothing till he was Post Grad RA and started again in November. Some progress in segmentation now.	Jan 2023: NO UPDATE
	2016/2017				
	Studies through CSG			Previous Updates	Latest Update
7	Identifying risk factors for poor speech outcomes following palate surgery	David Sainsbury davidsainsbury@mac.com		Jan 2022: Data extraction complete and first draft of manuscript complete. Poster presented at CFSGBI 2021. Abstracted submitted to Cleft 2022.	Jan 2023: Oral presentation at International Cleft Conference, Edinburgh, July 2022. Manuscript submitted to CPCJ January 2023.
8	Investigating auditory and linguistic processing in children with cleft palate and articulation problems	Steph van Eeden stephanie.vaneeden@nhs.net	NIHR CDRF funding	Jan 2022: Four sites now open and awaiting the 5th – 55 participants recruited, and data on >40 so far. Recruitment will end 30 April 2022.	Jan 2023: Recruitment and data collection complete. N=105 (95 cleft, 10 non-cleft speech sound disorder). Dissemination: Oral presentations - Cleft Speech CEN (Nov 2022); Early Childhood Voices conference (Dec 2022) Poster presentations – NIHR conference (Nov 2022) Papers still to be submitted and presentations at Craniofacial Conference Thesis submission due May 2023
	2018				

9	Participation in decisions relating to craniofacial care: the experiences of children with craniosynostosis, their families and the professionals who work with them.	Sarah Kilcoyne Sarah.Kilcoyne@ouh.nhs.uk	£50,000 for a research associate	Jan 2022: Project due to recommence in February 2022.	Jan 2023: Currently at University of Oxford CUREC ethics review.
10	The effects of being born with a cleft lip and/or palate on mealtime behaviours.	Matthew Hotton Matthew.Hotton@ouh.nhs.uk		Jan 2022: Recruitment continued to be significantly impacted by lack of patient contact in MDT clinics & lack of uptake. Recent amendment allows for advertisement through CLAPA. Hoping to hit our target by spring/summer 2022	Jan 2023: The study was completed in spring 2022 and results presented at Edinburgh 2022. Hoping to write up for publication in due course.
11	Assessing social communication skills in children with craniosynostosis: a longitudinal study of Autism Spectrum Disorder	Sarah Kilcoyne Sarah.Kilcoyne@ouh.nhs.uk		Jan 2022: Paper in final stages of preparation.	Jan 2023: Paper in final stages of preparation

12	Fetal facial assessment and cranial evaluation with advance Ultrasound and MRI Evaluation of novel three dimensional MRI for fetal facial and cranial examination of dysmorphic features; a pilot study and comparison with state-of-the-art ultrasound	Jacqueline Matthew Jacqueline.matthew@kcl.ac.uk Andrew Wilkie andrew.wilkie@imm.ox.ac.uk	NIHR CDRF funded	Jan 2021: My application to the NIHR CDRF round was successful and I began my fellowship in September 2020. I am currently working on setting up a retrospective observational study looking at antenatal MRI assessment of craniofacial anatomy (ethics in place). I have just been awarded a college of radiographers research grant to conduct PPI (qualitative) research into perceptions, experiences and barriers to pregnancy imaging research in diverse racial groups (currently applying for university level ethics). I will shortly begin an ethics application for a prospective US and MRI comparison study due to begin July 2022. No update 2022	Jan 2023: The data collection for the retrospective fetal craniofacial MRI data has been completed, and I am continuing with data analysis. An oral presentation related to this preliminary work has been accepted at the International Society of MRI in Medicine Conference 2023, Toronto, titled : *Automated atlas-based craniofacial biometry for 3D fetal MRI: multi-acquisition comparison of fetuses with Down syndrome and a control cohort.* I have completed prospective clinical trial data collection on 25 paired MRI and US fetal scans between 20-37 weeks GA, to compare craniofacial feature visibility and biometry across modalities using new 3D methods. I am currently in review phase with this data and the study may be extended to collect another 5-10 datasets.
13	The Early Assessment of Speech Outcomes in 3-year-old children with Cleft Palate +/- Cleft Lip (CPL)	Beth Fitzpatrick Beth.Fitzpatrick@bch.nhs.uk		Jan 2022: Data Analysis stage took longer than anticipated. X2 presentations at ACPA Conference 2021 X3 abstracts submitted for Cleft 2022 International congress In the writing up stage. Thesis submission aim: July 2022	Jan 2023: • PhD viva examination completed Jan 2023 • Completing minor corrections • X2 presentations at Cleft 2022 completed • X1 presentation at EUROCRAN January 2023 Aim to publish results of the study but no time frame as currently on maternity leave
	2019				
	Studies through CSG			Previous Updates	Latest Update

14	SLUMBRS Optimal sleep position for babies with CP	Sharon Williams – trial coordinator sharon.williams4@mft.nhs.uk Iain Bruce – study lead lain.bruce@manchester.ac.uk	NIHR funded and portfolio Trial registration number: NCT04478201	Jan 2022: Sites across the UK are about to open. Residual problem with oximetry equipment from Masimo is causing current delay. Metryka A, Cuniffe C, Evans HJ, Gavlak JG, Hudson N, Kirby N, Lakhanpaul M, Lin YL, Murray C, Rajai A, Robson H, Schilder A, Walsh T, Bruce I. Study protocol for randomised clinical trial comparing the effectiveness of side-lying sleep positioning to back-lying at reducing oxygen desaturation resulting from obstructive sleep apnoea in infants with cleft palate (SLUMBRS2). BMJ Open. 2021 Apr 7;11(4):e049290. doi: 10.1136/bmjopen-2021-049290. PMID: 33827851; PMCID: PMC8031693.	Jan 2023: 9 sites now open and recruiting. 4 sites still in set up 12 patients have been recruited. An application has been made for an 18-month study extension.
15	Are there variances in the early communication behaviours of infants born with different cleft types?	Holly Peryer holly.peryer@nhs.net		Jan 2022: Abstract submitted to the International Cleft Congress Edinburgh 2022.	Jan 2023: Presented at the International Cleft Congress July 2022. Study completed.
16	Optimising surgical outcomes in cleft lip/palate through linking Cleft Collective Cohort study data with national registry and NHS digital data	Yvonne Wren yvonne.wren@bristol.ac.uk		Jan 2022: Work looking at phenotype validation was presented at the Craniofacial Society of Great Britain and Ireland conference in September 2021 and is currently in the early stages of being written up as a paper. Access to NHS Digital is still on hold while the Cleft Collective secures additional funding.	Jan 2023: This study was not funded and therefore work has not progressed. I would suggest that this study can therefore be archived.
17	Visualising and measuring facial expressions in 3D	Jane Kerby Jane.kerby@nhs.net		Jan 2022: We have started recruiting to the trial. 75 patients to date recruited. Recruitment ongoing.	Jan 2023: Pilot study completed. Ongoing work with collaborators who are now in Glasgow university.

18	Cleft Care UK Studies	Yvonne Wren yvonne.wren@bristol.ac.uk		Jan 2022: The planned application by Andy Ness was not pursued. Yvonne is now preparing an application focused entirely on cleft to submit to the NIHR to look at adolescent outcomes. Progress towards this has been helped by funding from University Hospitals Bristol and Weston NHS Trust to carry out focus groups with groups of clinicians and also with young people born with clefts to determine what content should be included in a future research clinic for adolescents.	Jan 2023: Following on from the focus groups, an application to the NIHR Programme Grants for Applied Research has been submitted. The title of this application is *Improving outcomes by addressing variation in unmet needs at transition to adult care for young people born with cleft lip and palate (Short title: Cleft@20)* This application has been shortlisted to stage 2 and has had positive reviews. The final outcome will be known in April. If the bid is unsuccessful, alternative funders will be sought.
19	Smoking decline and the incidence of cleft lip	Matt Fell mattfell@doctors.org.uk		Jan 2022: One year spent with the Cleft Collective on this project. First two elements of the triangulation have been published (1. Systematic review and 2. Ecological study/Natural experiment). Final element is the mendelian randomisation which is awaiting the Cleft Collective Maternal Cleft GWAS to be ready for use and will be presented at CLEFT 2022 and hopefully published shortly afterwards.	Jan 2023: No progression since 2022. Aim remains to use Cleft Collective Maternal GWAS for Mendelian Randomisation study.
	2020				
20	ECLiPS – Auditory processing parental questionnaire (nested study within cleft collective)	Stephanie van Eeden stephanie.vaneeden@nhs.net		Jan 2022: Study opened in Spring 2021. Only 23 respondents so far – low response rate (9%). One more year of data collection.	Jan 2023: Study closed to recruitment and data collection Jan 2023. Total 168 participants. Analysis to start summer 2023 with aim to write up autumn 2023.

21	Covid Cleft	Neil Brierley neil.brierley@nhs.net		Jan 2022: • Funding granted from the Edinburgh Clinical Trials Unit for managing the RedCAP database • Endorsed by the Royal College of Surgeons of England • Data collection to date: – 8 units entering data – 651 operations details entered – Data entry closed on 7 June 2021 • Oral presentation at CFSGBI 2021 • Submitted for presentation at International Cleft Meeting 2022	Jan 2023: NO UPDATE
	2021				

22	Understanding and improving the decision-making process regarding surgery for parents of children with non-syndromic craniosynostosis at the Oxford Craniofacial Unit.	Corah Lewis corah.lewis@hmc.ox.ac.uk		Jan 2022: Recruitment and data collection commenced. Questionnaire provided to health care professionals.	Jan 2023: Data collection and analysis complete. Submitted as part of Doctorate, will be written up for publication in due course. The following recommendations will be communicated to the service: 1. To explore a process of putting parents currently considering surgery for their child in touch with consenting parents who have recently been through the decision-making process. 2. To look into whether it is feasible for parents to meet with Nursing and/or Psychology after their initial appointment where surgery is discussed to clarify their understanding of all the relevant information. 3. For all MDT members to be mindful of single parents who may have limited opportunity to talk this decision through with someone close to them. 4. Where possible, to incorporate pictures of older children (who did and didn't opt for surgery) into the pictures shown in clinic to give parents an insight into how their child might look as they grow older. 5. To develop a decision aid document or written summary of

					the clinic appointment to aid with retention and sharing information with significant others.
23	Parents' experiences of empowerment throughout the treatment of syndromic craniosynostosis.	Hannah Thornhill H.Thornhill@liverpool.ac.uk		Jan 2022: Sponsorship from the University of Liverpool granted. Due to submit for ethical approval shortly.	Jan 2023: Recruitment completed. Write up is underway. To be presented at the Craniofacial conference.
24	The cost of cleft care for the parent and child	Dr Melissa Padashi-Fard ft20184@bristol.ac.uk			Jan 2023: Focus groups carried out (Dec 2021) & data analysed - which informed the development of a national questionnaire. Questionnaire data has been collected (Dec 2022) & currently being analysed. Thesis is due for submission September 2023. Research will subsequently be submitted for publication in a peer reviewed journal & possibly presented at the British Orthodontic Society 2023.
25	Sleep and language development in children with isolated cleft palate	Dr Victoria Knowland vic.knowland@newcastle.ac.uk			Jan 2023: Rejected for funding from Rosetree Trust. Looking into two possible other funding avenues.

26	Exploring the Experience of Parents Whose Children Have Been Diagnosed with Single-Suture Craniosynostosis (SSC): A Focus on Protective & Risk Factors for Psychological Wellbeing	Ms Gemma Hall gemma.hall@liverpool.ac.uk		Jan 2022: Finalising NHS ethics. Liaison with Headlines and beginning some additional PPI consultation on project	Jan 2023: Ethics was granted mid-2022 and recruitment has now been finalised, with 15 families having been recruited from two NHS sites and via word of mouth. Due to start write-up with the goal of ultimately preparing manuscript for submission to peer-reviewed journal.
27	HARMONY – HeAlthieRsMiles fOr childreN with cleft bY improving tooth decay prevention and management	Mr Gormley alexander.gormley@bristol.ac.uk	NIHR Doctoral Fellowship	Jan 2022: Awaiting NIHR funding review.	Jan 2023: Fellowship commenced November 2023. Fellowship project is made of four workstreams: 1) Overview of reviews of interventions to prevent and manage caries 2) Epidemiological analysis of the CleftCollective cohort 3) Qualitative analysis of facilitators and barriers to good oral health in children with cleft 4) Co-production study to design a complex intervention to prevent and manage caries in children with cleft

28	Transverse interdental arch outcomes of 5-Year-Olds born with a UCLP following changes in cleft services within the United Kingdom	Dr Alattar Batol gp20177@bristol.ac.uk			Update pending.
	2022				
29	What are the needs of and barriers for young people (YP) born with a Cleft Lip +/or Palate (CL/P) who want to post photographs of themselves on social media.	Mrs Julie Davies julie.davies@mft.nhs.uk		New study	Jan 2023: Study is being completed as part of an MSc in Health Psychology. Study is going to use a method called photo-elicitation to discuss how the young people feel about their appearance. The study has just been submitted to ethics. Data collection will take place in late February/March 2023 and the study will be written up by the end of June 2023 for submission to Staffordshire University as part of the Masters degree.
30	Prevalence of dental caries and associated factors amongst children with cleft lip and/or palate and the impact of two different sustained intervention approaches in UK and India.	Mrs Madhavi Seshu Madhavi.Seshu@alderhey.nhs.uk>		New study	Jan 2023: Making amendments to the proposal, Planning to resubmit for funding in September/October 2023.

	Other relevant studies				
	TOPS	Kevin Munro kevin.munro@manchester.ac.uk	NIH funding NIHR portfolio	Jan 2022: First main papers of this study have been submitted.	Findings disseminated at International conference in Edinburgh 2022. Main paper submitted to New England Journal of Medicine
	Genetic basis of cranial malformations	Andrew Wilkie andrew.wilkie@imm.ox.ac.uk	NIHR portfolio We have been fortunate to raise 3 external grants (VTCT Foundation, £200k, 1.11.19-30.04.22; Great Ormond Street Hospital Charity, £169k, 1.04.20-31.03.21; MRC, £774k, 1.11.20-31.04.24). This secures the research programme for the immediate term.	Jan 2021: Recruitment: This has fallen to near zero over the past year because of covid-19. Going forward, we will target recruitment to patients of particular clinical interest, rather than attempting blanket recruitment. Even post-covid, recruitment numbers likely to fall to ~25% of levels achieved during middle of 2010-20 decade Publications: Over the past year, we have played leading roles on publications on GWAS in metopic synostosis (*Human Genetics*, PMID 32266521; *SMAD6* mutations (*Genetics in Medicine*, PMID 32499606 and *SIX1* mutations (*Journal of Medical Genetics*, PMID 33436522) No update 2022	Jan 2023: Recruitment: Recruitment has continued to focus on probands attending the Oxford Craniofacial Unit and other individuals/families of particular clinical interest. 69 probands recruited 1/1/21-19/5/22. No data update since May '22 as no research nurse support available. Publications: Since 1/1/21, 11 relevant publications (PMIDs: 33074973, 33565190, 33904513, 33993607, 34310431, 34429528, 34758253, 35627201, 35761471, 36178483, 36543535). Highlights included demonstration that researcher-led investigation more than doubled the number of clinical molecular diagnoses for patients with craniosynostosis in the 100,000 Genomes Project (increase of 112%), and description of the first heterozygous deletions of *ERF* and homozygous loss-of-function in *SPRY1* in patients with craniosynostosis.

	Grant application: The Cleft Collective Cohort Study	Yvonne Wren and Cleft Collective yvonne.wren@bristol.ac.uk	The Underwood Trust	Jan 2022: In the last year, the Cleft Collective team have been successful in securing funding from MRC to investigate the rates and causes of neurodevelopmental and mental health problems in children born with clefts. While this will contribute some funding support to the Cleft Collective, it does not provide the level of core funding needed to sustain the study. Additional funding from the VTCT Foundation and the Underwood Trust have been sourced as bridging funding to supplement the funds from the Scar Free Foundation, who remain committed to the study. Discussions re future support from funders are ongoing.	Jan 2023: We are very pleased to report continued funding for the Cleft Collective has been provided by the Underwood Trust to sustain recruitment and data collection to 2027. Recruitment has now passed 10,000 total participants from over 3500 families. The 12-year questionnaire has been finalised and sent out to all parents of participants aged 12 or over. We are now working on the content of the 15-year questionnaire and welcome involvement from psychologists in the development of this. We are keen to promote use of the dataset and welcome proposals.
	Cleft Collective Speech and Language Study (CC-SL), a nested study within the main Cleft Collective group of cohort studies. Improving outcomes for children with persistent speech disorder: Understanding the impact of identified risk factors and intervention.	Yvonne Wren and Cleft Collective yvonne.wren@bristol.ac.uk	The Underwood Trust	Jan 2022: Recruitment and data collection are ongoing. All data collected are made available to the research community and to date 9/42 proposals have included requests to specifically access the speech and language data within the Cleft Collective. The survey developed as part of the work originally outlined in this proposal to CSG is now live however data collection was initially paused as a result of Covid and more recently, as a result of needing to secure ethics amendment for changes to how we ask services for SLT intervention information at age 5.	Jan 2023: Along with the main Cleft Collective study, funding for ongoing recruitment and collection of data will be provided by the Underwood Trust until 2027. Recruitment is still considerably lower than pre-pandemic times and in some sites, has still not restarted. The intervention survey has been restarted and will be sent out to teams and community SLTs imminently. Current recruitment is over 1000 from over 500 families.

	CRANE	Craig Russell Sophie Butterworth			NO UPDATE

Study complete and findings disseminated

Study complete with some dissemination still outstanding

Study recruitment and data collection complete, analysis still underway

Study recruitment and data collection still underway

Study has ethical approval but yet to start

Study in early stages

~~**Appendix 3**: Slumbrs report May 2023.~~

~~Recruitment to study is low. 12 sites now open but only 13 babies recruited~~
~~Many centres reporting complex babies who do not meet the eligibility criteria or falling numbers of babies.~~
~~2 centres have had issues with ICT and clinical Governance.~~
~~Slumbrs have tried to support this with many meetings with the centres.~~
~~The CI, Iain Bruce, informed us on 18th April that RfPB (Results for patient benefit) would not award the requested 18 month costed extension at this stage as they want stronger evidence that Slumbrs can recruit to target. They suggested a no cost 6 month extension as the next step. The sponsoring trust have agreed to the no cost extension.~~

~~Helen Robson: PI Slumbrs North Thames~~

~~Date of next meeting: September 27th 2023.~~

Appendix D Cleft Lip and Palate Association Update

Cleft Lip and Palate Association Update

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Cleft Development Group meeting
12th May 2023

#SaveCLAPA

In our last update we told you about our #SaveCLAPA appeal that we launched in October 2022. Months of dwindling income left us with two choices – make drastic cuts to vital services or raise a huge amount of money fast. The middle of a cost-of-living crisis felt like the worst time to ask, but our community deserved to know how desperate the situation was and how badly we needed help. I'm delighted to tell you that the #SaveCLAPA campaign was very successful and raised over £100k, allowing us to end 22/23 without a financial deficit and more importantly increase the number of people giving to us monthly so we have an increased income we can rely on.

However I wish I could say that was the end of it – that we're safe and secure now and can stop worrying. Sadly, this isn't the case and, as a group that has always been so supportive of CLAPA, we want you to know the truth which is, if we go back to the way things were, it won't be long before we're in that same scary place again.

As you all know only too well, cleft isn't going anywhere and, as such, there will always be a need for the services CLAPA provides. I don't want the future of these services to ever be in doubt again. I want CLAPA to be something that the cleft community can rely on year after year, generation after generation.

To do this, we need your help. If you are not already making a monthly donation, you can help us that way (www.clapa.com/donate), but you also help by raising awareness not only of CLAPA's service but our charitable status and need for funding. CLAPA receives no government or NHS funding and as a small charity with a tight budget, even one bad month can spell disaster.

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As I previously updated we do have a fantastic new Head of Income, Mikaela Conlin-Hulme who, thanks to a generous grant from the VTCT foundation, is in the process of finalising the new Income Generation Strategy.

Cleft Lip and Palate Awareness Week 2023

6th-14th May is Cleft Lip and Palate Awareness Week, and hopefully you've already seen our posts and updates across our social media channels (@clapacommunity on Instagram, Facebook and Twitter). Our aim is to get our myth-busting videos and other posts in front of as many eyes as possible this week, and I'm delighted to say that halfway through the week we've already reached 200,000 people!

The community response has been truly incredible this year, with thousands of patients, parents and carers posting about their own cleft journey to help raise awareness in their networks.
There's still time to get involved – please share CLAPA's posts along with a message about why you're supporting Cleft Lip and Palate Awareness Week this year.

For more information and updates, visit www.CLAPA.com/AW23.

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Step up for Cleft Lip & Palate
As part of Awareness Week, we also have a live virtual fundraising challenge event underway – Step Up for Cleft Lip & Palate. This challenge has had a bit of a face lift from previous names and a rebrand from Step up for CLAPA to make it clearer what the cause is and to increase the awareness it can raise!

The challenge this year is for the community as a whole to get involved and do a loop of all the NHS cleft Clinics in the UK! Yes that's 1464 miles! Participants (113 at the time of writing this) can form

teams, family groups or even go it alone and can run, walk, hop, skip even salsa the distance! I'm taking part and have 35 miles to cover by the end of the week! Everyone taking part has been sent a pin badge and a list of conversation starters about cleft so they can raise pounds and awareness! So far, we have raised over £8,400!
It's not too late to take part as we are running the challenge up to the 14th May! Full details can be found at www.clapa.com/stepup.

Staffing Changes
We are in the process of recruiting for 3 new members of staff – a Data Officer, Fundraiser and Finance Officer. Interviews have been held for all positions and appointments are in the process of being made.

For the full staff team, please go to https://www.clapa.com/about-us/meet-the-team/.

CLAPA Trustees
We have recently advertised for 3 new Trustees – a Clinician, someone with a comms, media or PR background and a charity sector professional. We have had a really good response and shortlisting is currently taking place with a view to interviews being held this month.

For the full board of Trustees, please go to https://www.clapa.com/about-us/meet-the-team/board-of-trustees/.

CLAPA Link people
We now have a CLAPA Link person in place for virtually every Cleft Team – thank you for all your help in achieving this!
We are keen to understand if this role is working and if the information that we are sharing is being disseminated within teams.

Please contact Ellie Dale, Engagement and Services Manager, at ellie.dale@clapa.com for more information or to nominate someone as the link to your service.

CLAPA Finances
We are currently in the process of finalising the Annuals Account for the financial year ending 31st March 2023. The financials are reporting an in year surplus (2022: in year deficit) with the reserves above 3 months (our reserves policy is 3-6 months). The Annual Accounts will be audited in June, and once agreed at the AGM, they will be available to share.

Claire Cunniffe
Chief Executive
claire.cunniffe@clapa.com

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